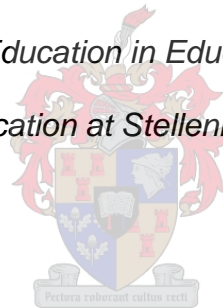


The experiences of a student with cerebral palsy  
at a higher education institution:  
a case study

by

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*Thesis presented in partial fulfilment of the requirements for the  
degree of Master of Education in Educational Support in the  
Faculty of Education at Stellenbosch University*



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March 2017

## DECLARATION

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Alison Welch Bucholz

March 2017

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## DEDICATION

For Tatjana



## ACKNOWLEDGEMENTS

I would like to thank the following people for accompanying me on this journey:

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- My supervisor, Estelle Swart, for her unwavering patience and invaluable guidance throughout my somewhat detoured tour.
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It would have been a lonely, if not impossible, journey without you all.

## ABSTRACT

Across the world, the inclusion and support of all students in mainstream education systems is accepted as a basic human right. Although access to higher education institutions for students with physical impairments has improved over the last two decades, in line with the Salamanca Statement and the United Nations Convention on the Rights of Persons with Disabilities, full inclusion of students with physical impairments at higher education institutions is yet to be realized. The purpose of this critical narrative inquiry was to investigate the experience of one student with cerebral palsy at a higher education institution in order to gain valuable insights into the nature of support required for future students with similar physical impairments in higher education. A critical emancipatory paradigm was adopted incorporating qualitative life history case study methodology. Interviews and the co-researcher's disability poetry formed the primary sources of data for this inquiry. In order to convey the true essence of the co-researcher's story, narrative and thematic data analyses were utilized. The key message to emerge from this inquiry is that students with physical impairments are a heterogeneous group, and as such, need to be supported individually by means of a social relational approach to disability. Higher education institutions need to play a pivotal role in creating pathways to success for these students by creating socially cohesive environments and by applying universal design for learning principles systemically.

**Key words:** critical disability study in education; higher education; inclusion; cerebral palsy; case study; student's experience; social relational model; pathways to success; universal design for learning.

## OPSOMMING

Die insluiting en ondersteuning van alle studente in hoofstroom onderwyssisteme word wêreldwyd as 'n basiese mensereg aanvaar. Alhoewel toegang tot hoërondewysinstansies vir studente met liggaamlike gestremdheid die afgelope twee dekades in lyn met die Verklaring van Salamanca en die bepalings van die Verenigde Nasies se Konvensie oor die Regte van persone met Gestremdheid verbeter het, moet volle inklusie vir studente met liggaamlike gestremdheid by hoër onderwysinstansies nog verwesenlik word. Die doel van hierdie kritiese narratiewe studie is om ondersoek in te stel na die ervaringe van een student met serebrale gestremdheid by 'n hoërondewysinstansie om sodoende insig te verkry in die aard van ondersteuning wat benodig word vir toekomstige studente met soortgelyke gestremdhede by hoërondewysinstansies. 'n Krities geëmansipeerde paradigma is ingespan wat kwalitatiewe lewensgeskiedenis gevalstudie metodologie behels. Die primêre bron van data was onderhoude en die digkuns van die mede-navorser. Ten einde die deelnemer se verhaal te ondersoek is narratiewe en tematiese dataverwerking aangewend. Die hoofsaak wat uit hierdie ondersoek aan die lig kom, is dat studente met gestremdhede 'n heterogene groep is en dus individueel ondersteun moet word vanuit 'n sosiaal-relasionele benadering tot gestremdheid. Hoërondewysinstansies speel 'n deurslaggewende rol om die weg na sukses te baan vir hierdie studente deur sosiale kohesie in omgewings te bevorder en beginsels van universele leerontwerp toe te pas.

**Slutelwoorde:** kritiese gestremdheidstudie in opvoedkunde; hoërondewys; inklusie; serebrale gestremdheid; gevalstudie; ervarings van studente; sosiaal-relasionele benadering; weg na sukses; universele leerontwerp

## TABLE OF CONTENTS

DECLARATION .....	i
DEDICATION .....	iii
ACKNOWLEDGEMENTS .....	iv
ABSTRACT .....	v
OPSOMMING .....	vi
TABLE OF CONTENTS .....	vii
LIST OF APPENDICES .....	xi
LIST OF TABLES AND FIGURES .....	xii
CHAPTER 1: CONTEXT AND RATIONALE OF THE STUDY .....	1
1.1 PREAMBLE .....	1
1.2 INTRODUCTION .....	1
1.3 OVERVIEW OF THE STUDY .....	2
1.4 PROBLEM STATEMENT, PURPOSE AND RESEARCH QUESTIONS .....	4
1.5 DESIGN AND METHODOLOGY OF THE STUDY .....	5
1.6 THE RESEARCHERS .....	6
1.7 ASSUMPTIONS .....	6
1.8 STRUCTURE AND PRESENTATION .....	7
1.9 CONCLUSION .....	7
CHAPTER 2: PHYSICAL DISABILITY AND HIGHER EDUCATION .....	8

<b>2.1</b>	<b>INTRODUCTION.....</b>	<b>8</b>
<b>2.2</b>	<b>THEORETICAL FRAMEWORK.....</b>	<b>8</b>
<b>2.3</b>	<b>CEREBRAL PALSY.....</b>	<b>14</b>
<b>2.4</b>	<b>RESILIENCE AND STUDENTS WITH IMPAIRMENTS.....</b>	<b>17</b>
<b>2.5</b>	<b>INCLUSIVE TRENDS .....</b>	<b>18</b>
2.5.1	International developments.....	20
2.5.2	South African developments .....	22
<b>2.6</b>	<b>STUDENTS WITH DISABILITIES IN HIGHER EDUCATION .....</b>	<b>26</b>
2.6.1	Access and throughput .....	26
2.6.2	Support services for SU students with impairments .....	28
2.6.3	Literature on students with physical impairments in Higher Education .....	29
<b>2.7</b>	<b>CONCLUSION .....</b>	<b>32</b>
	<b>CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY .....</b>	<b>33</b>
<b>3.1</b>	<b>INTRODUCTION .....</b>	<b>33</b>
<b>3.2</b>	<b>RESEARCH DESIGN .....</b>	<b>34</b>
3.2.1	Rationale for a critical, emancipatory paradigm.....	35
3.2.2.	Purpose of the study.....	38
3.2.3.	Context of the study.....	38
3.2.4	Rationale for qualitative research methodology .....	39
3.2.5	Selection of participant / co-researcher .....	41
<b>3.3</b>	<b>ETHICAL CONSIDERATIONS.....</b>	<b>42</b>
<b>3.4.</b>	<b>REFLEXIVITY .....</b>	<b>44</b>
<b>3.5</b>	<b>DATA COLLECTION.....</b>	<b>44</b>



3.5.1	Existing literature .....	46
3.5.2	Informal and semi-structured interviews .....	46
3.5.3	Poetry as data .....	49
3.5.4	Additional artefacts .....	50
<b>3.6</b>	<b>DATA MANAGEMENT AND ANALYSIS.....</b>	<b>50</b>
3.6.1	Narrative analysis .....	51
3.6.2	Thematic analysis .....	53
3.6.3	Research criteria of the study .....	55
<b>3.7</b>	<b>CONCLUSION .....</b>	<b>57</b>
	<b>CHAPTER 4: FINDINGS OF THE STUDY .....</b>	<b>58</b>
<b>4.1</b>	<b>NARRATIVE ANALYSIS.....</b>	<b>58</b>
4.1.1	Introduction.....	58
4.1.2	Pre-university.....	58
4.1.3	University.....	62
4.1.4	Future prospects.....	70
<b>4.2</b>	<b>PRESENTATION OF THE THEMATIC FINDINGS .....</b>	<b>71</b>
4.2.1	Internal barriers.....	71
4.2.2	External barriers .....	73
4.2.3	Support creating pathways to success.....	76
4.2.4	Tatjana's reflections and advice to students with physical impairments .....	80
<b>4.3</b>	<b>CONCLUSION .....</b>	<b>84</b>
	<b>CHAPTER 5: DISCUSSION AND RECOMMENDATIONS.....</b>	<b>86</b>
<b>5.1</b>	<b>INTRODUCTION.....</b>	<b>86</b>
<b>5.2</b>	<b>IMPLICATIONS OF THIS STUDY .....</b>	<b>86</b>

<b>5.3</b>	<b>RECOMMENDATIONS FOR FURTHER RESEARCH .....</b>	<b>91</b>
<b>5.4</b>	<b>STRENGTHS OF THE STUDY .....</b>	<b>91</b>
<b>5.5</b>	<b>LIMITATIONS OF THE STUDY.....</b>	<b>92</b>
<b>5.6</b>	<b>CONCLUSION .....</b>	<b>92</b>
	<b>REFERENCES .....</b>	<b>94</b>
	<b>APPENDIX A.....</b>	<b>108</b>
	<b>APPENDIX B.....</b>	<b>114</b>
	<b>APPENDIX C.....</b>	<b>118</b>
	<b>APPENDIX D.....</b>	<b>119</b>
	<b>APPENDIX E .....</b>	<b>120</b>
	<b>APPENDIX F .....</b>	<b>121</b>
	<b>APPENDIX G.....</b>	<b>122</b>
	<b>APPENDIX H.....</b>	<b>126</b>
	<b>APPENDIX I .....</b>	<b>127</b>
	<b>APPENDIX J .....</b>	<b>129</b>
	<b>APPENDIX K.....</b>	<b>130</b>
	<b>APPENDIX L .....</b>	<b>131</b>
	<b>APPENDIX M .....</b>	<b>132</b>
	<b>APPENDIX N.....</b>	<b>133</b>

## **LIST OF APPENDICES**

- Appendix A: SU policy regarding students with special learning needs/disabilities
- Appendix B: SU Disability Unit 2016 brochure
- Appendix C: Institutional information letter
- Appendix D: Institutional permission to carry out research
- Appendix E: Participant information letter
- Appendix F: Participant's letter to the ethics committee
- Appendix G: Participant's informed written consent form
- Appendix H: Letter of approval for ethics clearance
- Appendix I: Interview guide and time-line sample
- Appendix J: Extract from transcribed interviews
- Appendix K: Example of initial coding from the transcripts
- Appendix L: Step 1 of thematic networks
- Appendix M: Example of a thematic network of a global theme and organizing themes
- Appendix N: Photographs illustrating Tatjana's mobility on campus

## LIST OF TABLES

Table 2.1: SU degrees awarded to students with disability status: 1996 – 2012 .....	28
Table 2.2: SU students registered with disability status: 1996 – 2012 .....	29
Table 3.1: Tatjana's biographical data .....	43

## LIST OF FIGURES

Figure 2.1: Tatjana viewed from a medical model stance .....	9
Figure 2.2: Tatjana's world viewed from a social model stance.....	10
Figure 2.3: The social relational model: Tatjana in context .....	12
Figure 2.4: The bio-psychosocial approach to a classification of Tatjana's functioning.....	13
Figure 2.5: Subtypes of CP .....	16
Figure 3.1: Graphic illustration of the research design of this study.....	35
Figure 3.2: Graphic illustration of the data collection process of this study.....	45
Figure 3.3: Graphic representation of the data analysis process of this study. ....	51
Figure 4.1: The limited campus Tatjana knew .....	72

## LIST OF ACRONYMS

AfriNead	African Network on Evidence-to-Action on Disability
CHE	Council on Higher Education
CP	Cerebral Palsy
CRPD	UN Convention on the Rights of Persons with Disabilities
DHET	Department of Higher Education and Training, South Africa
DoE	Department of Education, South Africa
DSD	Department of Social Development, South Africa
FOTIM	Foundation of Tertiary Institutions of the Northern Metropolis
HEDSA	Higher and Further Education Disability Services Association, South Africa
HEI	Higher Education Institution
ICF	International Classification of Functioning, Disability and Health
SU	Stellenbosch University
UD	Universal Design
UDL	Universal Design for Learning
UN	United Nations
UNESCO	United Nations Educational, Scientific, and Cultural Organization
USB	Afrikaans acronym for SU Risk Management and Campus Security Service
WG	Washington Group on Disability Statistics
WHO	World Health Organization

# CHAPTER 1: CONTEXT AND RATIONALE OF THE STUDY

## 1.1 PREAMBLE

I first met my research participant and co-researcher, Tatjana, in 2008. She struck me as a capable, confident, independent young woman eager to become a teacher; eager to make a difference in young children's lives. Tatjana had experienced numerous setbacks and barriers since she started her studies one year prior to our meeting. She had successfully negotiated and overcome some of the barriers on her own, though ongoing difficulties seemed to be the story of her life as a person with a physical impairment and specifically as a student with cerebral palsy (CP) in Higher Education (HE).

Running parallel to Tatjana's story, I had started my Master's thesis with the intention of studying learners with physical impairments in mainstream schools, but I was uncomfortable with the idea of documenting the learners' experiences as an outsider. I did not want the participants to be seen as mere objects of my study. Who was I to interpret their experiences as a non-disabled adult? This troubled me. Hence, it was a turning point for me when I came across articles and books on disability studies in education – specifically on critical disability studies, which spoke to me. I could relate to the notion of including the research participant as a consultant or partner in the research process - to allow the person with a disability's voice to be heard accurately.

I asked Tatjana to be my co-researcher. She agreed unreservedly and thus our journey as researchers began.

## 1.2 INTRODUCTION

“All human beings are born free and equal in dignity and rights.”

(Hurst, 1998)

Students with physical impairments are people first and foremost. They, like people without impairments, share an inherent need to be viewed and treated as equal - to enjoy the same rights and opportunities - to be included.

With this in mind, this critical disability study in education (DSE) focuses on a student with CP's experience of inclusion in HE. The intention was to understand one student with CP's experience of studying at a higher education institution (HEI) in order to facilitate the development of more inclusive practices for other students with similar physical impairments in HE. In addition, this study sets out to be an emancipatory experience for the student - my co-researcher Tatjana - to allow her voice to be heard. A critical, emancipatory research paradigm was adopted, incorporating the social relational model of disability as a theoretical framework. Qualitative methodology was used to investigate the thesis topic in the form of a participatory life history case study. Tatjana volunteered to participate, being a student with CP in HE who was eager to share her story in order to facilitate change. Data were generated primarily through unstructured, informal interviews and Tatjana's disability poetry.

This chapter begins with an overview of the background and context that frame the study. Thereafter, the purpose of the study, the problem statement and the research questions are presented, followed by an outline of the research design and methodology. My perspectives and assumptions are also included in this chapter, concluding with the structure and presentation of the study.

### **1.3 OVERVIEW OF THE STUDY**

This is an educational support study framed within DSE, which is a fairly new field (Connor, Gabel, Gallagher & Morton, 2008). Although the broader field of Disability Studies (DS) has been in academia for four decades, DSE has only emerged over the last two decades. What appealed to me about DSE (as opposed to traditional special education research) is that DSE aims to strengthen the understandings of the daily experiences of persons with disabilities<sup>1</sup> in schools and HEIs, establishing and maintaining accessible and

---

<sup>1</sup> Generally, in line with disability etiquette, people first language (or disability friendly language) was adopted in this study. The phrases "people (or persons) with physical impairments", "students with physical impairments" and "individuals with disabilities" are used frequently, though, the term "disabled student" is also used in parts of this study when citing other authors or organisations, for example. These latter phrases are used interchangeably in DSE literature and legislations referring to disability. Within the social model of disability, the term "disabled people" is preferred.

inclusive educational environments (Connor et. al., 2008). Furthermore, DSE aims to include young people in education as active social agents of change. Young people with impairments are frequently not consulted in studies about themselves – their opinions and experiences remain marginalised and hidden (Phillips, 2011, p. 364). DSE seeks to remedy this problem.

As the academic world does not exist apart from society, it may be assumed that the same exclusionary elements present in society in general are present in HE too. However, research regarding students with physical impairments' experiences of inclusion in HE is limited abroad (Beauchamp-Pryor, 2012; Chataika, McKenzie, Swart & Lyner-Cleophas, 2012; Fuller, Healey, Bradley & Hall, 2004; Goode, 2007; Haihambo, 2010; Macleod & Cebula 2009; Sachs & Schreuer, 2011) and in South Africa (Bell, 2013; CHE, 2005; Crous, 2004; Howell & Lazarus 2003; FOTIM, 2011; Matshedisho, 2007a, 2007b; Rule & Modipa 2011; Swart & Greyling, 2011).

Although some of the latter studies do indicate that there has been progress in the inclusion and support of students with physical impairments at HEIs, incongruities between the theory of inclusive education and its practice remain evident (Artiles, Kozleski, Dorn & Christensen, 2006; DHET, 2012b; Howell & Lazarus, 2003; Losinsky, Levi, Saffey & Jelsma, 2003).

Although policies are in place, it is apparent that students with physical impairments are yet to experience full inclusion at HEIs on international and national levels.

In 2008, Greyling undertook one of the initial studies of the experiences of students with physical impairments in HE at Stellenbosch University (SU). Greyling's (2008, p. 112) findings were that there is a crucial need to continue to listen to and act upon the voices of students with physical impairments in combined efforts to make HE more inclusive. In Swart and Greyling's (2011, p. 105) article that stemmed from Greyling's 2008 study, they reiterate the need for follow-up research that should be done, by not "othering" the students but rather gaining insights from them. They added that this research should preferably be designed in partnership with and by the student participants.

In 2010, Koch carried out research at SU on how students with physical impairments adapt socially. This was one of the first studies with this particular focus. Koch's conclusion was



that consulting with students with physical impairments before any decisions can be made on their behalf is important. Her findings echo Greyling's.

In Greyling's study, an interpretive paradigm with a qualitative research methodology framework was used. Greyling (2008, p. 112) suggests in her conclusion that alternative designs and mixed designs and methodology could also contribute to different perspectives, including narrative and critical research. More recently, Bell's (2013) study on students with hearing impairments experiences in HE in the Western Cape supports these earlier recommendations. Bell adds that:

In terms of research methodology, students with disabilities should be empowered to conduct their own research and to participate more actively in the research process. This would allow them to be active researchers or participants rather than "research subjects". (p. 259)

This study, therefore, endeavoured to add another dimension to Greyling's, Koch's and Bell's local research by tackling the topic from a critical participatory narrative approach in order to facilitate change.

## **1.4 PROBLEM STATEMENT, PURPOSE AND RESEARCH QUESTIONS**

Research indicates that although there have been significant improvements concerning access to and support in HE for persons with physical impairments, students with physical impairments in HE are yet to experience full inclusion. Research also indicates that in order for these students to be included fully, they need to be consulted during the inclusion process (Lange, 2005, p. viii).

The purpose of this participatory case study was, therefore, twofold: firstly, to investigate and to understand the inclusive experiences of an individual student with CP studying at a HEI. Societal, institutional and personal barriers and successes were investigated in order to identify where better inclusive practices could be developed and carried out; and secondly, to create an emancipatory space for the research participant to tell her story in order to be heard.

The primary research question which guided this study was:

What was Tatjana's experience of inclusion at university?

To shed more light on the problem, the following sub-questions were asked:

1. What was Tatjana's experience of barriers to learning?
2. What was Tatjana's experience of support?
3. What were Tatjana's personal successes at university?
4. What are Tatjana's and the literature's recommendations to improve inclusive practices, especially for students with similar physical impairments in HE?

## **1.5 DESIGN AND METHODOLOGY OF THE STUDY**

This study was framed within social relational disability theory to acknowledge the social aspect of disability but also individual impairment. Qualitative methodology was used to investigate the thesis topic through a narrative inquiry in the form of a participatory life history case study. The research took place at SU in South Africa. The inclusive experiences of one student with CP (Tatjana) were investigated. Tatjana volunteered to be part of this research and was the primary source for generating the case study data. Informal interviews with Tatjana were carried out over a two-month period. A time-line illustrating Tatjana's life story was used as a point of departure. Tatjana's journal extracts, extracts from previous letters and emails to lecturers and support staff were drawn upon, and Tatjana's disability poetry was included to add a creative dimension – an expressive arts research method where poems are seen as narratives of the lived experiences of participants (Furman, 2004).

Two types of data analyses were executed: firstly, narrative analysis was applied, followed by thematic analysis. During the narrative analysis, Tatjana's first person accounts shaped the narrative "text" (Merriam, 1998, p.157) - her language was used to tell the story and the emphasis was on how she told the story. Following this process, during the thematic analysis, the data was coded and organized into thematic networks.

## **1.6 THE RESEARCHERS**

During the initial period of conducting this study, I was employed as a part-time tutor and administrator at SU. I tutored BEd Honours students on Inclusive Education. I also acted as Tatjana's test and examination scribe for a couple of years until I was appointed as a full-time administrator. I therefore, brought to this research study my personal experiences of students' perceptions of inclusive practices and my relationship with Tatjana as her scribing faculty liaison person. I concede that although my experiences may have aided in providing valuable insights into Tatjana's experience of inclusion, they had the potential to cloud or bias my interpretations of the findings. I was also aware of my position as a non-disabled adult researcher within DSE. In order to avoid these elements of subjectivity and positioning, I engaged in critical self-reflection (Bloomberg & Volpe, 2008, p. 41) by regularly contemplating the study and the process, jotting down my thoughts in my research journal and being monitored and guided closely by my supervisor. In addition, to further ensure the credibility of the research study, more than one method of data collection and analysis was used. It was furthermore hoped that Tatjana's participant involvement role would add credibility to the findings.

Since this was a DSE, Tatjana took on the role of co-researcher or partner. The study was thus participatory in nature. According to Merriam (2009, p.4), participatory research is a type of research that includes participants in the design and execution of the research. Tatjana therefore played a key role in the research process. She was asked to proof read my drafts at intervals and to provide commentary on the accuracy of the data recording, analysis and interpretation. I, however, remained the primary researcher for the purpose of assessing this thesis.

## **1.7 ASSUMPTIONS**

It was anticipated that the knowledge generated from this study would confirm existing research findings of similar studies as well as provide new valuable insights, thus informing HE practice. In addition, it was assumed that Tatjana would find the participatory experience liberating and that this study would serve as a form of support for other students in similar positions, who might understand Tatjana's position, identify with her story and consequently tell their own story (Phillips, 2011, p. 373) in order to facilitate

change. The intention was not, however, to foreground a resilient disabled heroine (Hiranandani, 2005, para 6) but rather to share one student with CP's story with others, to learn from her experiences.

## **1.8 STRUCTURE AND PRESENTATION**

The process of investigation of this study was as follows:

Chapter 1 introduces the context of the study, the problem statement, and the research purpose and research questions. It also covers the research approach, assumptions, and the organisation of chapters.

Chapter 2 discusses the theoretical framework and provides a review of relevant literature in disability studies and inclusive practices in HE.

Chapter 3 covers the research paradigm, research design and methodology.

Chapter 4 presents the findings of the study.

Chapter 5 concludes the thesis with a discussion and recommendations.

## **1.9 CONCLUSION**

This chapter has provided an overview of the study. First, the background and context of the study are covered. Thereafter, the problem statement, the aims and objectives and the primary research question are stated. The research design and methodology are touched on, to be further developed in Chapter 3. The chapter concludes with an outline of the structure and presentation of the study. The following chapter focuses on the theoretical framework of this study and a review of the literature relating to inclusion and disability in HE.

## **CHAPTER 2: PHYSICAL DISABILITY AND HIGHER EDUCATION**

### **2.1 INTRODUCTION**

The purpose of this chapter is to discuss key models of disability briefly in order to develop a suitable theoretical framework for this study; to highlight the unique nature of CP and explore a rhizomorphic approach to support; to consider the newer socioecological approach to defining resilience; to look at the global and local developments of inclusion in order to contextualize this study; to impart information regarding physical disability in HE on international and national levels; and to demonstrate the paucity of research regarding students with physical impairments in HE overall, hence the need for this study.

### **2.2 THEORETICAL FRAMEWORK**

The CHE (2005, p. 1) explains that how one views disability affects who one defines as having an impairment, the prevalence of impairment in one's society and hence the scope of the pool of students with impairments. This in turn influences what is required at an institutional level to guarantee equity for students with impairments and to ensure that any form of discrimination is prevented. I therefore discuss two of the most influential models of disability (namely, the medical model and the social model) in the next section, briefly to provide a backdrop to my rationale for adopting the social relational model of disability as my theoretical framework.

The dominant model of disability in most countries up until the latter part of the twentieth century was the medical model. The medical model's main premise is that impairment is a biological reality and that disability is situated within the individual body. Categorisation and intervention approaches focus on the individual's functional limitations, the subsequent effect of these on the individual's everyday activities and existence, and on cure and care (Williams, 2001, para. 11). This deficit or individual model of disability has profoundly influenced the manner in which health care and the education of persons with impairments have been approached worldwide. Within this model, disability is portrayed as an individual's personal tragedy caused by reduced function (Reindal, 2008, p. 141). One of the many pitfalls of the medical model is that this model of disability plays down the relational and social nature of disability and fails to acknowledge diversity within

impairments (Terzi, 2005, p. 203). Furthermore, the medical model of disability and the basic premises of inclusion are in opposition, as the medical model infers separation of persons with impairments into special needs classes or schools, excluding them from society (Bell, 2013, p. 21), whereas inclusion promotes full integration of persons with impairments as valued students, which is the aim of DSE.

Figure 2.1 illustrates the limitations of the medical model. Using Tatjana as an example, the emphasis on the problem lying within the individual and the strong focus on medical intervention are highlighted, with social influences not being taken into account.

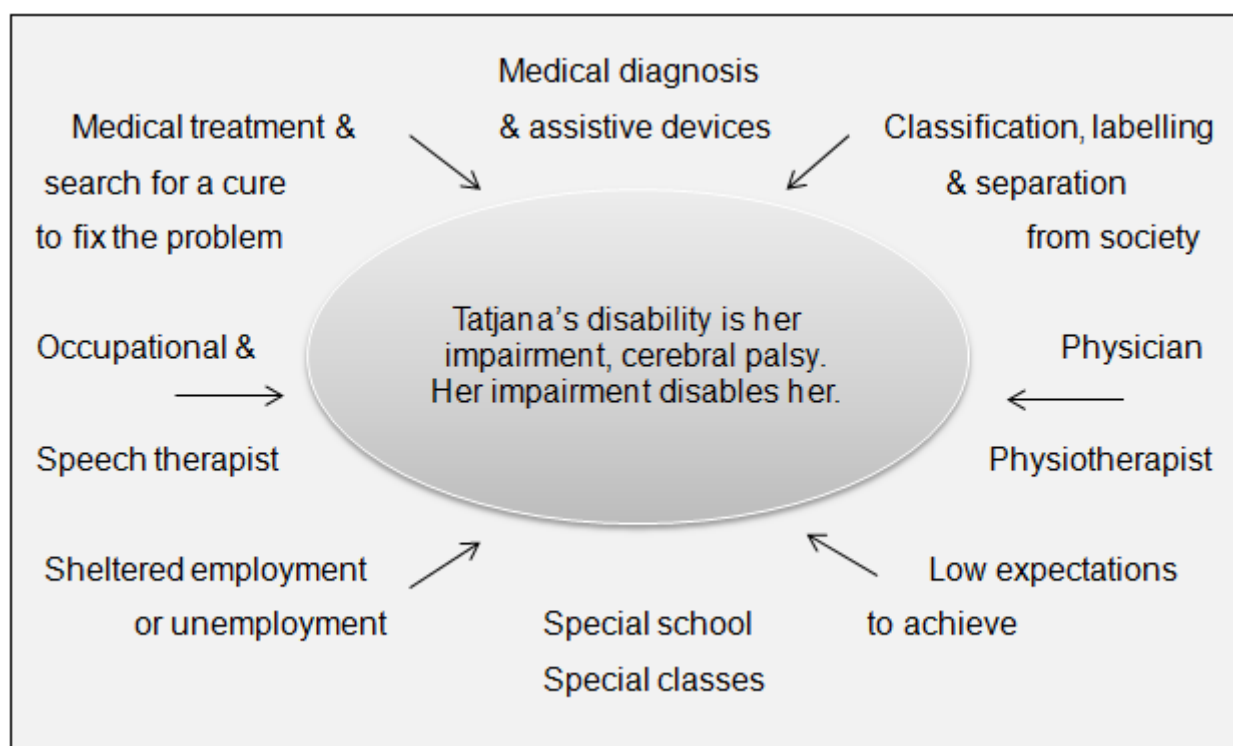
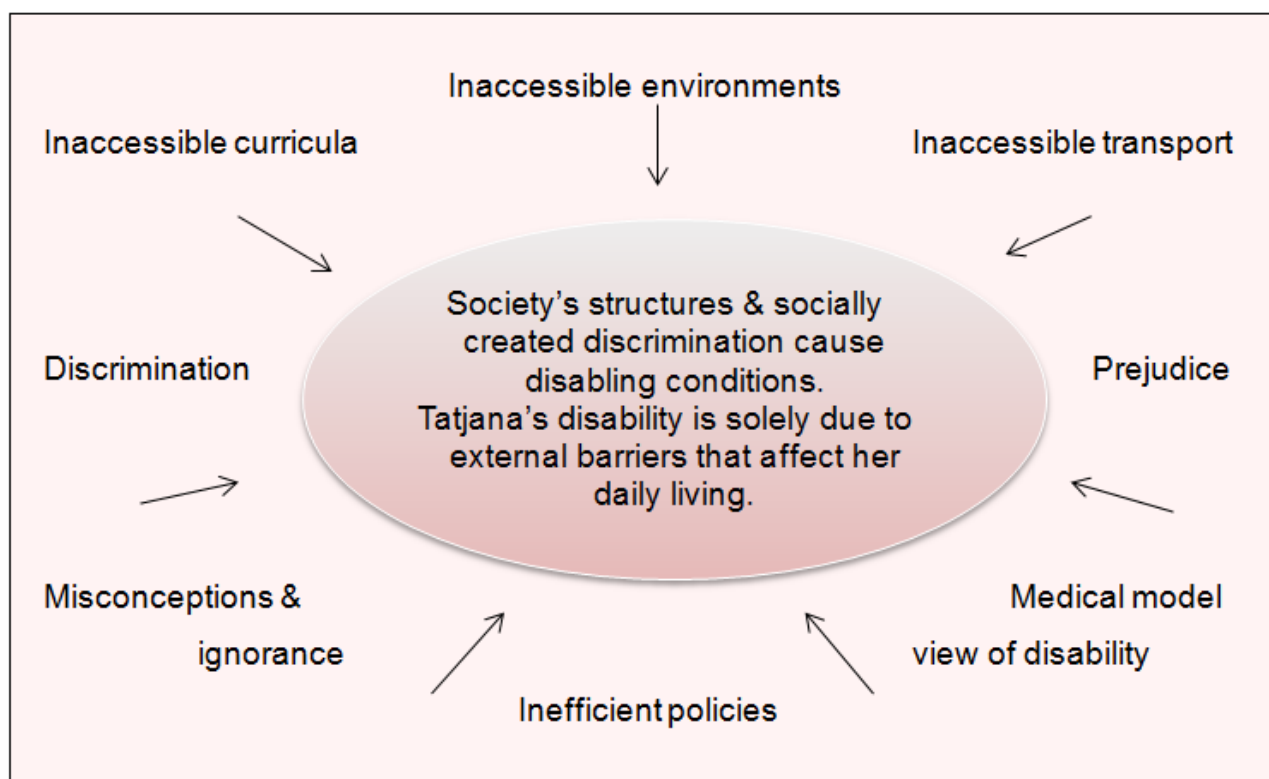


Figure 2.1: Tatjana viewed from a medical model stance (adapted from <http://attitudes2disability.wordpress.com/category/medical-model-vs-social-model/>)

The social model on the other hand, takes the opposite view. The social model, which has played a key role in DS and disability movements in more recent times, was developed by the *Union of Physically Impaired Against Segregation* (UPIAS) and academic disability activists (in particular, Finkelstein, Hunt, Oliver and Barnes) in opposition to the medical model. Those promoting a social model of disability define disability as a social construct. According to Lange (2005), "This model sees the circumstances of people with disabilities

and the discrimination they face as a socially created phenomenon which is not related to the impairments of disabled people” (p. vi). The extreme version of this argument is that if society were to change, disability would cease to exist (Williams, 2001, para. 52). Figure 2.2 illustrates society’s oppressive impact on individuals with impairments, which is central to this model.



*Figure 2.2: Tatjana’s world viewed from a social model stance (adapted from <http://attitudes2disability.wordpress.com/category/medical-model-vs-social-model/>)*

Although the social model has played a pivotal role in creating a collective identity and liberating persons with impairments (Shakespeare, 2006b, p. 199), there has been growing critique of this model of disability among DS scholars over the last two decades (e.g. Farrell, 2010; Gabel & Peters, 2004; Reindal, 2008; Shakespeare, 2006a, 2006b; Terzi, 2005; Thomas, 2003, 2004a). The social model’s weakness is that it over-socialises the causes of disability by claiming that disability is merely a limitation of activity, resulting from discriminatory social structures and attitudes (Terzi, 2005, p. 202). Consequently, the social model neglects to address the complexities of impairment and how these complexities affect abilities. For example, several impairments have elements of pain or

fatigue which impact on the everyday lives of certain individuals with physical impairments (Terzi, 2005, p. 202). This is not factored into the social model.

A number of alternative approaches have been developed in reaction to the weaknesses of the social model. For example, Shakespeare (2006a) proposes a critical realist approach, Swain and French (2000) promote an affirmative model of disability, Gabel and Peters (2004) explore the notion of resistance theory, Terzi (2005) calls for a capability approach (which is based on Nussbaum and Sen's capability approach) and Thomas (2004a) and Reindal (2008) suggest a relational interpretation of the social model - the social relational model.

For the purpose of this study (and considering the limited scope of a mini-thesis), I chose the social relational model as my theoretical framework, since both the impact of context and the impact of the individual impairment are considered, which is important to this study. In addition, I believe that the social relational model of disability conforms well to the inclusion principle of social justice, as the main concern of the social model, that being oppression, is not omitted (Reindal, 2008 p. 135). Thomas (2004a, p. 569) points out that a social relational understanding of disability was initially intended by Hunt and Finkelstein, early pioneers of the social model, but that this understanding went off course over time. Thus, this choice of framework is also in keeping with the essence of DS.

The dynamic relational or circumstantial interplay between "impairment" and "disability" is the key element of the social relational model of disability. Figure 2.3 on the following page illustrates how Tatjana's world is viewed within a social relational framework. In this model, impairment plays a role in causing restricted activity. "Disability" comes to the fore when the constraints of activity that individuals with impairment experience are socially inflicted. However, there is not necessarily a causal effect in play (Terzi, 2005, p. 214).

In Figure 2.3, numbers 1 and 2 indicate areas where definitions and classifications would be suitable and numbers 3 and 4 indicate areas for making modifications to the environment in order to foster inclusivity, and to reduce the effects of issues related to number 4 from occurring. All four areas are dynamic as there is continuous interplay between the different levels. Certain facets of the necessary conditions of reduced function may be able to be modified by advances in treatment and assistive devices, and



adaptations to the environment could alter the conditions for becoming disabled (Reindal, 2008, p. 144).

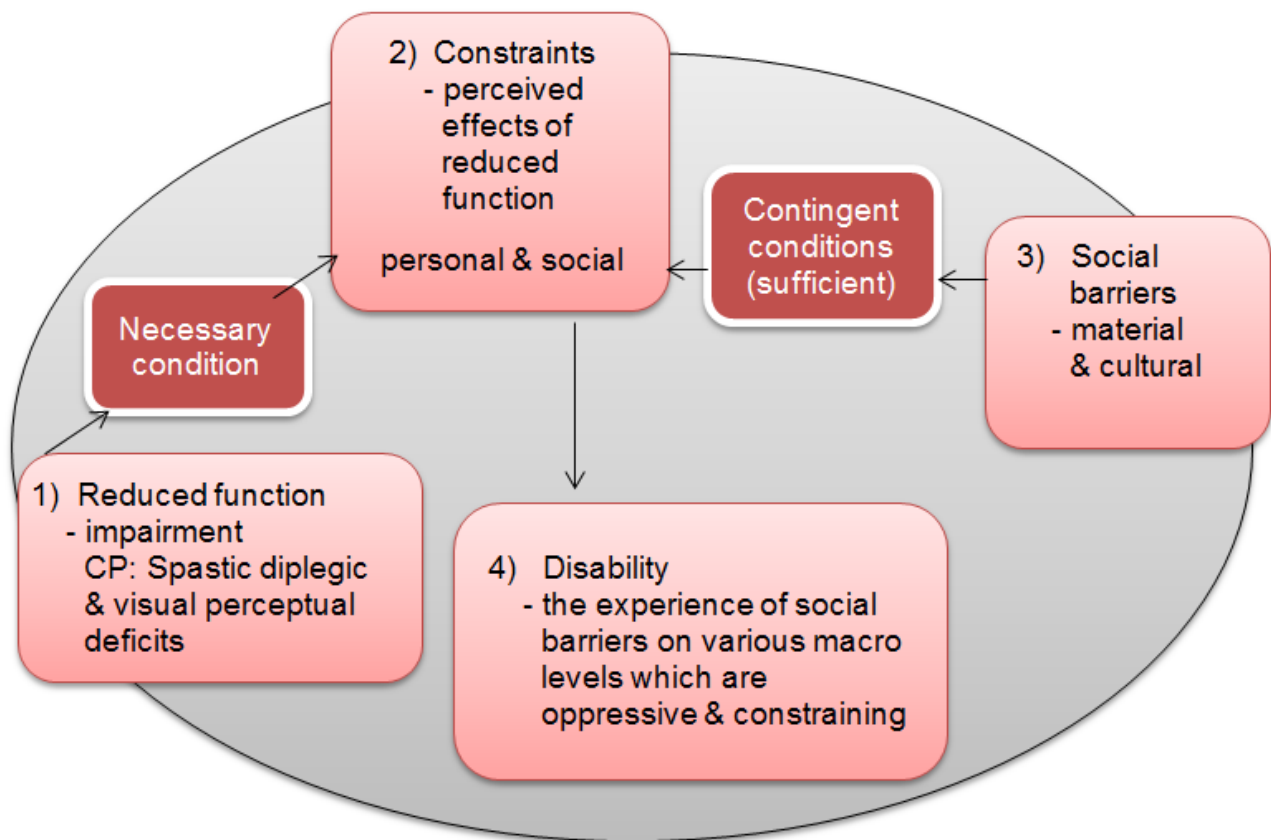


Figure 2.3: The social relational model: Tatjana in context (adapted from Reindal, 2008, p. 143)

The social relational model includes similar aspects of the capability approach to disability in the sense that both these models emphasise the importance of the disabled person's capacity to function, empowering the person through their capabilities (what they *can* do), and they both emphasise the important element of human dignity (Bell, 2013, p. 24).

The World Health Organisation's (WHO) current approach to classifying functioning and disability, laid out in the International Classification of Functioning, Disability and Health (ICF), is an attempt to view disability more holistically (WHO, 2001), as opposed to viewing the condition purely from a narrow bio-medical model as was done in the past.

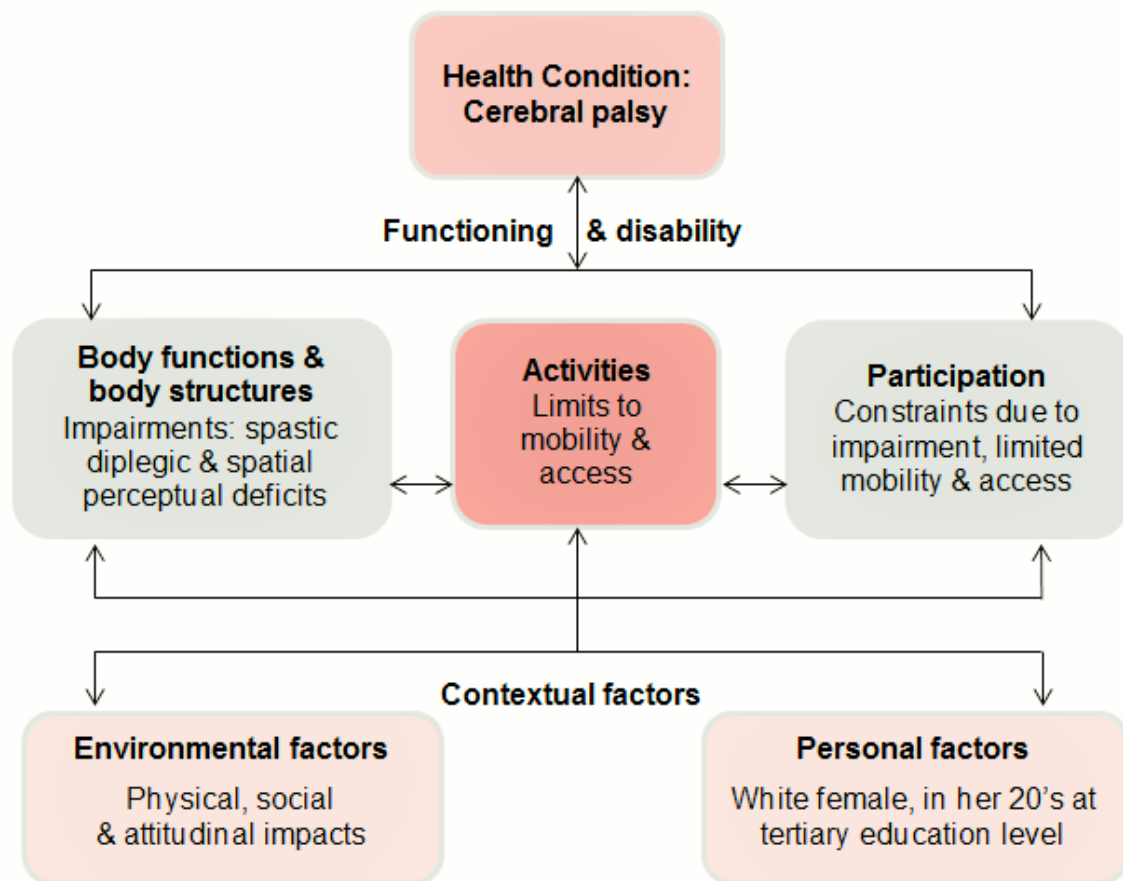


Figure 2.4: The bio-psychosocial approach to a classification of Tatjana's functioning and disability (adapted from the WHO's ICF, 2001, p. 18)

The ICF adopts a bio-psychosocial approach to classifying function and disability. This new approach to the classification of functioning places each person with an impairment or health condition within a context, since the individual's ability and disability are seen as the direct result of the interaction between the health conditions of the individual and their environment (WHO, 2013, p. 4). This approach is consistent with other models of support which stress the importance of the dynamic interaction between the individual and their environment and the impacts thereof (such as Bronfenbrenner's bio-ecological model), and has tenets similar to those of the social relational model. One of the criticisms of the ICF model, however, is that it portrays the interplay between impairment and disability as that of *restriction* (Thomas, 2004b, p. 578). According to Reindal (2008, p. 138), disability is then seen as a form of *disadvantage* and not a form of *oppression*. Reindal sees this model as insufficient, as its goals for participation rely on norms and statistics and it

therefore lacks the promotion of autonomy and enablement. However, other research, albeit from the medical field, indicates that the WHO's ICF bio-psychosocial approach is a useful one for units to incorporate when supporting students with CP, as it factors in the influences of context and the environment and shifts the focus away from cause and charity. Rosenbaum and Stewart (2004, p. 8) state that the ICF is a valuable tool for informing decision-making processes and to determine meaningful outcomes for individuals with CP. They welcome the inclusion of the influence of environmental factors, as the contexts in which people live have major effects on their functional abilities (Rosenbaum & Stewart, 2004, p. 9). In addition, they argue that considering social and cultural contexts is essential in making sound decisions, since the attitudes, values and beliefs of others influence participation in everyday activities. Figure 2.4 illustrates how Tatjana's functioning and disability would be viewed from a bio-psychosocial approach, striving for optimal functioning and social engagement.

Before moving onto the next section, it is important for the context of this study to mention that the South African disability movement and the South African dispensation currently consider disability from a social model stance. This approach to disability is evident in the emphasis on the reformation of society in government policies so that society may be able to address persons with impairment needs aptly (Lange, 2005, p. vi). Bell (2013, p. 21), however, reports that although the social model has been adopted in recent governmental policies pertaining to disability, the medical approach to support is still clearly evident in the regulations, discourses and services provided at most South African HEIs (see also Luna, 2009).

The section that follows addresses CP briefly and highlights the need for a case specific approach to the support of students with CP.

## **2.3 CEREBRAL PALSY**

In order to understand Tatjana's experience as a student with CP at a HEI comprehensively, CP and its characteristics and implications for education are discussed briefly in the following section.

CP is a physical impairment that affects movement, posture and coordination (Human Rights Watch, 2015, p. 3). More specifically, CP is

an umbrella term that describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems (Rosenbaum, Paneth, Leviton, Goldstein, Bax, Damiano, Dan & Jacobsson, 2007, p. 9).

CP is viewed as the main cause of childhood disability worldwide. World reports estimate that CP affects approximately 1.5 to more than 4 in 1000 children (CDC, 31 July, 2015).

CP is defined by certain functional characteristics (not by the original cause). However, a good understanding of the underlying cause and the selective vulnerability of damage to the foetal or infant brain at certain periods of brain development is helpful for the overall support and management of the individual with CP.

There are four recognised subtypes of CP: spastic CP, dyskinetic CP, ataxic CP and mixed CP<sup>2</sup>. Figure 2.5 illustrates these subtypes and the parts where the brain is damaged. The darker the shading is, the more severe the damage (Hoon & Tolley, 2013, p. 433).

The prominent characteristics of CP include a variety of limitations in mobility and hand use linked to evidence of neurological dysfunction (Hoon & Tolley, 2013, p. 424). It should be noted that even though CP is a non-progressive (static) disorder, regression in certain areas of functioning (including mobility) occurs into adulthood. An adult who has a dyskinetic form of CP may, for example, experience secondary compression of her spinal cord, which then leads to gradual weakness and loss in other bodily functions during

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<sup>2</sup> In Tatjana's case, she falls under the subtype spastic CP – more specifically, spastic quadriplegia. "The term spastic refers to the inability of muscles to relax leading mainly to the impairment of motor function. Quadriplegia on the other hand means that all four extremities as well as trunk and neck are affected" (Tatjana, 2008).

adulthood. Inhibited motor function in students with CP has serious implications for their education and socialisation (Krüger & Botha, 2016, p. 368).

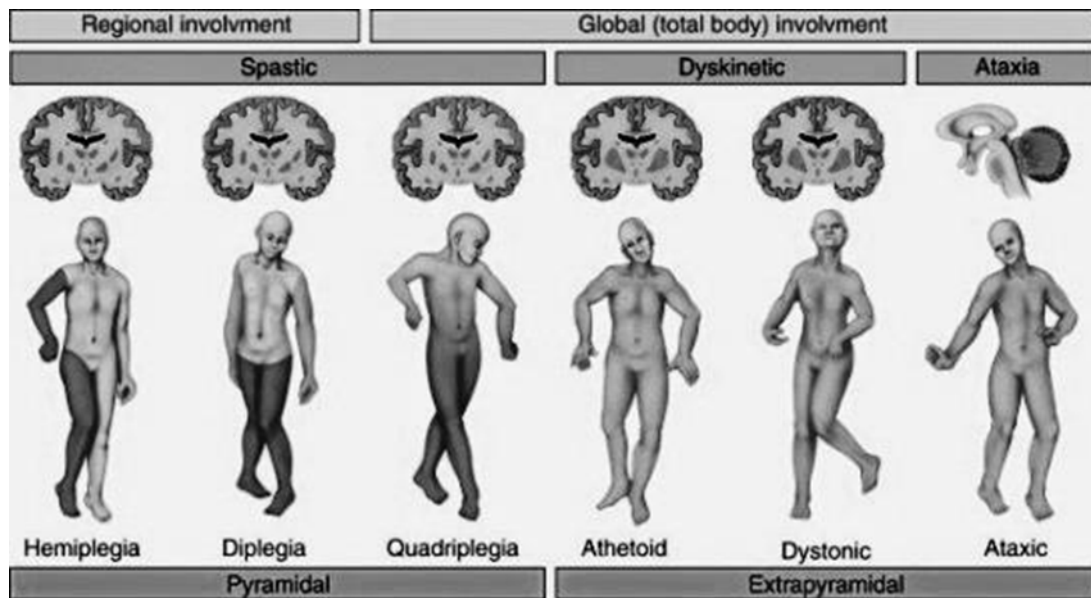


Figure 2.5: Subtypes of CP (Hoon & Tolley, 2013, p. 433)

Since there are varying degrees of severity in the manifestation of CP, individuals with CP have distinctively unique needs and experiences which are determined by a variety of internal and external factors (such as the individual's personality, nature of support required, and different life worlds or contexts). This makes CP a complex physical impairment with case specific challenges. Visser's 2013 (pp. xx, 228) study concerning the subjective experience of adolescents with CP verifies that the experience of disability by individuals with CP is indeed multi-faceted and that the need to be recognized and treated as unique is important. Sienko (2014) confirms this: "Although the diagnostic categorization of CP is homogenous, differences in functional ability and cognitive involvement contribute to heterogeneity in activities and participation for individuals with CP" (p. 2). The implication of this for the teaching, learning and support of individual students with CP at HEIs is far-reaching, as the type of support required for one person with an impairment cannot be generalised to the broader population of students with physical impairments.

Deleuze and Guattari's (1980) notion of the philosophical rhizome is a useful analogy to explain the nature of CP and the type of support needed for students with CP. Deleuze and

Guattari's rhizomatic theory describes society as being one of "multiplicities"<sup>3</sup>. Knowledge, practice and living are viewed as rhizomatic (Goodley, 2007, p. 145), forming themselves horizontally in a never-ending non-linear fashion like the intricate, multiple root system of the potato (as opposed to growing in a vertical fashion like the tree's linear root system). Within this analogy, the lives of individuals with CP would be construed as rhizomatic, "forming lines of flight that are always becoming" (Goodley, 2007, p. 145). No one individual's physical impairment is the same and no one support system follows the same path as another. The uniqueness and variability of the path and support are important and the process is ever changing and on-going. This idea of varying pathways of support for success ties in well with the newer conceptualisation of resilience, as discussed in the following section.

## 2.4 RESILIENCE AND STUDENTS WITH IMPAIRMENTS

Research shows that throughput and success rates of students with physical impairments at HEIs often include a resilience factor (e.g. self-determination in Anctil, Ishikawa & Scott, 2008; positive attitude, self-advocacy and self-determination in Lyner-Cleophas, Swart, Chataika & Bell, 2014, p. 3). The following section briefly describes *resilience* as a concept and highlights the more recent socioecological approach to resilience, the one emphasised in this study.

"Resilience" is understood broadly as "adaptive behaviour in the face of adversity" (Theron, Theron & Malindi, 2012, p. 63). Resilience has different meanings in different contexts and within different cultures. Viewed from the dominant ecological approach, resilience focuses on the individual and the individual's inherently resilient qualities. Hutcheon and Lashewicz (2014, p. 1383) contend that in the field of disability other understandings of resilience that include diverse modes of being need to be adopted. They propose that moving away from ability-centric and supercrip definitions of resilience towards a constructivist conceptualisation of resilience, are in line with DS (Hutcheon & Lashewicz, 2014, p. 1387). Resilience is then contextual, subjective and part of a

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<sup>3</sup> A unity that is, in its own right, multiple (Deleuze & Guattari, 1980, p. 8)

meaning-making process (Ungar, 2004, p. 342). Resilience is obtained through the “negotiations between individuals and their environments for the resources to define themselves as healthy amidst conditions collectively viewed as adverse” (Ungar, 2004, p. 342). This newer socioecological notion of resilience accommodates the multiplicities of individuals’ experiences of resilience (Ungar, 2004, p. 341), and, like the social relational model of disability, describes an interactive, dynamic process of being.

I, therefore, chose the socioecological approach to resilience for the purpose of this study because the socioecological definition of resilience sees the role of the individual’s impacting systems (i.e. the individual, peers, family, academic institution and community) as supportive, aiding positive results. These successes are enabled by creating opportunities and support systems for individuals with physical impairments to interact in meaningful ways with their impacting systems and in so doing, making it possible for these individuals to bypass possible hurdles which prevent them from succeeding (Liebenberg, Ungar & LeBlanc, 2013, p. 131). Porcelli, Ungar, Liebenberg and Trépanier’s (2014) description of resilience factors of disabled youth as “Everyday patterns of (micro)mobilities<sup>4</sup> through home, school and community (which) help (them) create pathways to resilience” (p. 863) is a useful one to consider.

The following section covers international and national movements towards inclusive education and frames the position of students with physical impairments in HE today.

## **2.5 INCLUSIVE TRENDS**

Inclusion is a term frequently used in current times. It has become a universal (and in some cases a contentious) term epitomizing social justice and, as with many catchwords it has the potential to become hackneyed and hollow (Swart & Pettipher, 2016, p. 3).

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<sup>4</sup> (Micro)mobilities are “... everyday patterns of independent, assisted and contextualized movements within social spaces and physical places” (Porcelli et al., 2014, p. 863).



There is much debate worldwide regarding inclusion<sup>5</sup> in education. The range of definitions of inclusion to be found on this extensively researched topic is testimony to this. These different interpretations are largely due to the diversity of global contexts. Numerous authors (e.g. Chataika et al, 2012; Dyson, 2001; Mitchell, 2010; Swart & Pettipher, 2016; Walton, Nel, Hugo & Muller, 2009) therefore highlight the importance of taking context into consideration when developing and implementing inclusive practices.

The United Nations Educational, Scientific, and Cultural Organization's Salamanca Statement (UNESCO, 1994) describes inclusive education systems as systems that

recognize and respond to the diverse needs of students, accommodating both different styles and rates of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use and partnerships with their communities. (p. 11 – 12)

A range of support to equal the range of special needs experienced in every educational institution is stressed. In South Africa, the goal of inclusion is to fight all forms of exclusion in order to create a truly democratic society (Burden, 1995). This requires a complete paradigm shift, as it presupposes a total mind switch based on specific values (Booth & Ainscow, 2011), such as a *positive attitude* towards all people, *tolerance* for difference, *acceptance* of change, *compassion* and *respect* for equality and human rights, while embracing the concepts of access, participation and potential success for all.

Although the philosophy of inclusion has been the predominant philosophy of education in many countries since the latter part of the 20<sup>th</sup> century, it is not supported unreservedly by

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<sup>5</sup> The literature differentiates between “inclusion” and “inclusivity”. Forlin (2004, p. 196) contends that where inclusion is generally about including students with special educational needs into mainstream educational systems, inclusivity involves supporting *all* groups (non-disabled and disabled) within mainstream educational systems. Other writers differentiate between “inclusion” and “inclusive education” (e.g. Engelbrecht, 1999, p. 5). They view inclusion as the broad philosophy of inclusion within society and inclusive education as education systems that embrace the philosophy of inclusion and put it into practice. In this study the terms inclusion and inclusive education are used interchangeably. Inclusivity, to my mind is the ultimate aim, with all students being supported, irrespective of their abilities, within one system.



all. One of the critiques of inclusive education is that too much emphasis is placed on the social model versus the medical model (Lindsay, 2003). Lindsay (2003, p. 5) views this as problematic. He argues that too much emphasis on the social model leads to inclusion being portrayed as being about human rights only. Whether inclusion actually works in practice then becomes immaterial.

Counter-arguments made by those in favour of inclusion are provided by advocates of inclusive education who claim that the emphasis should be on the social context rather than on the individual's impairments (Mitchell, 2010, p. 5). According to these advocates, education should be characterised by a single education system that addresses all students' educational needs; and as Mitchell (2010) puts it so succinctly,

... since there is no clear demarcation between the characteristics of students with and without disabilities, and there is no support for the contention that specific categories of students learn differently, separate provisions for such students cannot be justified. (p. 5)

In addition, if one considers the issue of human rights, any form of segregation of students with physical impairments would be to withhold their human rights (Oliver, 1996). In a country like South Africa with its legacy of apartheid this issue is particularly deep-seated. It is therefore the position of this study that an inclusive education system is an essential prerequisite for the creation of inclusive, just societies (Barnes, 2010). In addition, the intersection of disability with race, culture, language and poverty makes it more complex in a developing country like South Africa (Lyner-Cleophas, et al., 2014, p. 1).

It is evident from the latter arguments that inclusive education is a multifaceted and challenging concept (Mitchell, 2010; Swart & Pettipher, 2016). The following section covers important international educational trends and developments.

### **2.5.1 International developments**

When considering developments in inclusive education, it is important to note that it is the broader idea of inclusion within society as opposed to the individual ethics of previous years that has influenced the move to inclusive education (Engelbrecht, 1999, p. 5). Dyson and Forlin (1999, p. 24) support this notion and add that inclusion stems from two

interconnected but clear-cut processes: broad social, economic and educational developments linked to the role of education in modern societies; and a general reconceptualization of the idea of disability, especially in the light of human rights and social justice. For example, the United Nations' strong emphasis on the rights of people with disabilities gave inclusion momentum in many spheres (Walton et al., 2009, p. 105). Inclusive educational ideals (contrary to the layman's belief) are not only about cost-effective practicalities and the physical placement of students with special needs into mainstream classrooms. Inclusive education ideals are deeply rooted "in liberal, critical and progressive democratic thought" (Engelbrecht, 1999, p. 7).

The World Conference on Education for All, 1990, held in Jomtien, Thailand, where inclusive education was the central point of discussion, signified a decisive moment for education worldwide. This key conference was followed by an equally critical world conference in Salamanca, Spain, in 1994. The message explicitly stated during these conferences was that the inclusion of all children, youth and adults into inclusive education systems is a universal right (UNESCO, 1994).

Other noteworthy international developments regarding inclusion and people with physical impairments are the United Nations (UN) 1994 General Assembly Resolution: *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*; UNESCO's 2000 Dakar Framework for Action addressing *Education for All: Meeting our Collective Commitments* and the United Nations 2006 Convention on the Rights of Persons with Disabilities (CRPD). According to Inclusion International (2010), the CRPD is a particularly significant convention as it presents both the framework and the obligations for finishing what the Salamanca Statement and Framework for Action originally initiated. The general principles of the CRPD are captured in Article 3, which are:

respect for inherent dignity, individual autonomy and independence of persons with disabilities, non-discrimination, full and effective participation and inclusion in society, respect for difference and acceptance of persons with disabilities as part of human diversity and humanity, equality of opportunity, accessibility and respect ... (United Nations, 2006).

Education is referred to in Article 24 of the CRPD. It specifically stipulates that governments are required to deliver education to children, youth and adults with disabilities at the same level as others; and to deliver education within an inclusive system at all levels. The fifth and last point of this article is particularly pertinent to this study:

States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation<sup>6</sup> is provided to persons with disabilities.

Furthermore, the UN (2010) claims that the acceptance of the CRPD and its Optional Protocol denote a clear and significant change in the way that disability is viewed from a deficit medical model to a social model of disability.

The subsequent 2016 UN document *Monitoring the Convention on the Rights of Persons with Disabilities, General comment No. 4 (2016), Article 24: Right to inclusive education* reiterates that barriers to education persist and that state parties must comply with the core principles of the CRPD (p. 2).

As these major developments were taking place on an international level, parallel fundamental developments were gaining momentum in South Africa. The following section provides a brief overview of local developments.

## **2.5.2 South African developments**

While 1994 was a significant year for many people with physical impairments worldwide, with the formulation of the Salamanca Statement's inclusive education principles, it was also a significant year for South Africans with the advent of a new South African democratic dispensation and its inclusive prospects. The inclusive education movement in

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<sup>6</sup>“Reasonable accommodation” refers to, “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden to ensure persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” (UNESCO, 2006).

South Africa is in keeping with worldwide developments but also facilitates the elimination of apartheid's exclusionary practices. As Hay and Beyers (2000) contend, with many South Africans having been excluded for so long by the previous colonial and apartheid systems, it makes sense that the drive for inclusion would be welcomed openly by the new South African dispensation, embracing a democratic society and a democratic education system, including HE. As a component of the democratization process of South Africa after 1994 (Hay & Beyers, 2000), the promotion of inclusion was initially incorporated into the new South African Constitution (1996). In the inclusive policies that were developed thereafter, one finds that due to South Africa's unique history of segregation and inequities, the South African policies of inclusive education have been influenced by a strong socio-political driving force (Swart & Pettipher, 2016, p. 18). The following policies and documents are of particular significance to this study:

- Education White Paper 3: A Program for the Transformation of Higher Education (DoE, 1997a).
- The Higher Education Qualifications Framework, Higher Education Act (HEA), No.101 (DoE, 1997b).
- Education White Paper 6, Special Needs Education: Building an Inclusive Education and Training System (2001a).
- Department of Education National Plan for Higher Education (DoE, 2001b).
- Department of Higher Education and Training Green Paper for Post-School Education and Training (DHET, 2012b).
- Department of Higher Education and Training White Paper for Post-School Education and Training (DHET, 2014a).
- Department of Higher Education and Training Draft Social Inclusion Policy Framework (DHET, 2014b).
- Department of Social Development *White Paper on the Rights of Persons with Disabilities* (DSD, 2016)

White Paper 6 (DoE, 2001a) presents a plan for inclusive education in South Africa as a way to attend to the plight of disability across the education spectrum, but, the primary emphasis is on schooling, and references to HE are mainly regarding access (DHET,

2012b, p. 54) and not support. However, the systems and practices of and for schools have a direct impact on learners transitioning from schools to HEIs.

According to the Department of Higher Education and Training's (DHET) Annual Report 2011/12, the HEA, Act 101 (1997b) stipulates an integrated national HE system and together with Education White Paper 3 (1997a), they form a foundation for the transformation of HE in South Africa, with the National Plan for HE (2001b) guiding the implementation thereof (DHET, 2012a, p. 19). Although brief references to inclusion of students with physical impairments are made in these documents, according to the Green Paper for Post-School Education and Training (DHET, 2012b), and despite the call for transformation and equity in these policies, the majority of students with physical impairments remain subjected to discrimination in the post-school education and training sector, including HE. This indicates that much work still needs to be done. Furthermore, the Green Paper also states that although admission trends reveal that social exclusion according to race and gender is decreasing, access and support for students with physical impairments are still limited (DHET, 2012b, pp. 10 - 11).

The DHET (2012b, p. 54) reports that part of the problem of disability in HE is that it is still handled in a disjointed way, separate from other transformation and diversity programmes. In addition, according to the Parliamentary Monitoring Group (PMG, 2011, para. 1), although South Africa ratified the CRPD in 2007, it has not satisfactorily integrated the Convention into its legal framework, which has reduced the weight of the Convention in South Africa considerably. At present, no national policy on disability is in place to direct education and training institutions in the tertiary sector. Commitment levels towards disability and the amount of resources apportioned to attending to disability issues therefore differ significantly between institutions (DHET, 2012b, p. 11). The DHET is consequently in the process of formulating a *National Disability Policy and Strategic Framework*, which will aim "to create an enabling and empowering environment across the system for staff and students with disabilities" (2012b, p. 54) and provide a standard for sound practice (DHET, 2012b, p. 55).

The recently issued White Paper for Post-School Education and Training (DHET, 2014a), which stemmed from the Green Paper, promises to formulate a strategic policy framework to direct the improvement of access to *and* success in post-school education and training

for people with physical impairments (DHET, 2014a, p. XV). This White Paper lays out a vision of a transformed post-school system (DHET, 2014a, p. 75) wherein the integration and support of students and staff with physical impairments in all facets of HE experience is addressed. One noteworthy recommendation in this White Paper is for, “the facilities and support services available to students and staff with disabilities in relation to individual requirements” in HE to be probed further (DHET, 2014a, p. 45).

Furthermore, the recent Draft Social Inclusion Policy Framework (DHET, 2014b) promises to aid public HEIs in formulating and sustaining their own policies on social inclusion<sup>7</sup> (DHET, 2014b, p. 7), incorporating the inclusion of students with physical impairments as one of the marginalised groups. This policy framework mentions a number of crucial elements that should be put in place for persons with physical impairments at HEIs. A few of the significant ones are:

- Operational Disability Units and effective Transformation Offices are to be established at all HEIs.
- Students with physical impairments rights are to be met by formulating policies that stipulate reasonable adjustments to be made to accommodate these students and by ensuring that the core staff of all institutions have student support staff as central figures
- Principles of Universal Design<sup>8</sup> for learning (UDL) are to be applied when modifying existing structures and when building new structures, as well as when considering transportation issues and the accessibility of residences.

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<sup>7</sup> Social inclusion is the all-inclusive development of society in which an enabling environment is established for the best development of all citizens, with particular attention to the most marginalised groups of society (Saloojee, 2001).

<sup>8</sup> “Universal design (UD) is the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Universal design for learning (UDL) includes assistive devices for particular groups of persons with disabilities where needed” (UNESCO, 2006).

- The norms and standards for the provision of infrastructure support for students with physical impairments are to be reworked by the DHET.
- National Guidelines for Persons with Disabilities in agreement with the CRPD are to be developed, as well as National Norms and Standards for Disability Units.
- Funding is to be made available for continuing research on access to, support and education of a wide spectrum of students with physical impairments.
- The DHET is to ensure that National Disability guidelines are being implemented at public HEIs and that annual reports indicating proposals for improvement are submitted to the Minister of Higher Education and Training

The recent *White Paper on the Rights of Persons with Disabilities* (DSD, 2016) addresses many of the above mentioned crucial elements and calls public, private and civil societies sectors to use this white paper as a means to accelerate inclusion transformation for people with physical impairments.

## **2.6 STUDENTS WITH DISABILITIES IN HIGHER EDUCATION**

As mentioned in Chapter 1, there has been progress in the access, inclusion and support of students with physical impairments at HEIs in South Africa and abroad due to important shifts in disability paradigms and the formulation of policies based on social justice and human rights. However, full inclusion for all students in HE is yet to be realised.

### **2.6.1 Access and throughput**

Statistics SA, applying the Washington Group Model, brought out a comprehensive report on persons with disabilities in South Africa during 2014, based on information collated during Census 2011. According to this report, South Africa's national disability prevalence rate in 2011 was 7.5 %, excluding children younger than five years old and persons with psycho-social and some neurological impairments. The findings in this study regarding tertiary education reveal that approximately 20% of severely disabled people aged between 20 – 24 years were attending tertiary education, with white students representing the highest percentage of the group and black students representing the lowest percentage (Statistics SA, 2014).



In 2014 approximately 5 087 students with impairments were enrolled at HEIs in South Africa (Lyner-Cleophas cited in Moses, 2014). This figure covers a wide spectrum of impairments, including physical, sensory, learning and psycho-social impairments. This, however, is not a true reflection of the number of students with impairments in HE during 2014, as many students do not disclose their impairments, and uniformity across South African universities with regard to the categorization of impairments or disabilities does not exist. Within specific institutions it is also evident that students with impairments are sometimes placed in one category when they could also fall under a number of other categories listed on the institution's disability categorization list. Tatjana, for instance, was placed in the category of "neurological disability", but, there is also a category named "cerebral paralysis"<sup>9</sup> and one named "mobility or orthopaedic disability" (see the SU disability categories listed in table 2.1). Tatjana has CP, which was caused by neurological brain damage, which in turn affects the functioning of her limbs, resulting in a mobility disability. She could therefore fall under any of the 3 categories. The category "other disability or condition" is also problematic as it is vague and the majority of students with disability status are recorded under this category.

The lack of reliable up-to-date data on disability in South Africa is concerning (DHET, 2014a, p. 45). It makes it difficult to measure progress in the realisation of the rights of persons with impairments.

The Washington Group on Disability Statistics' (WG) new series of disability questions, that was utilised in the Statistics SA 2011 report, focuses on activity limitations and social participation restrictions, aiming to produce internationally comparable prevalence measures in the future (former DWCPDs NDRP, 2013, p. 24). This new series of questions may be useful for South African HEIs to use in order to encourage uniformity in data categorization and thereby potentially lead to a better understanding of the disability

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<sup>9</sup> It is not clear from SU records whether this disability category refers to CP (i.e. whether it was translated from Afrikaans directly) or whether it refers to a cerebral condition that involves paralysis of a part/s of one's brain.



landscape which could in turn lead to better means of support being established across the board for students with impairments.

**Table 2.1: Number of SU students registered with disability status: 1996 – 2012**

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Number of students registered with disability status	42	41	52	53	55	58	78	92	130	144	181	192	239	277	333	324	355

Table 2.1 indicates the number of SU students with disability status registered at SU between 1996 and 2012. It is evident from Table 2.1 that the registration rate of students with disability status has increased considerably (from 42 in 1996 to 355 in 2012) which illustrates that *access* has improved since 1996. However, the number of students with disability status who *graduate* constitute only a fraction of the number who registered 3 to 6 years earlier. If one compares the registration figures in Table 2.1 to the number of students with disability status who completed their studies 3 to 6 years later (as reflected in Table 2.2), it appears that more than half of the students with disability status did not complete their studies.

As mentioned in the previous paragraph, Table 2.2 reflects the *throughput* rate of disabled and able SU students between 1996 and 2012<sup>10</sup>. The relatively low number of graduates with disability status in Table 2.2 indicates a clear under-representation of students with impairments, forming a notable minority (averaging 0.5%) of total SU graduates over this period. The attrition rate appears to be high.

### 2.6.2 Support services for SU students with impairments

In 2000, SU stated in their strategic framework that access and accessibility for students with impairments to the university was not what it should be and that continued attention would be devoted to the matter (SU, 2000, p.20).

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<sup>10</sup> SU Statistics available till 2012 were used in this study, since the focus was on Tatjana's experience at the institution from 2007 until her graduation at the end of 2012.

The SU's OSSLN (currently known as the Disability Unit) supports approximately 345 students covering a range of impairments (De Villiers, 2015). Viewed from the social model of disability, support provided by the OSSLN includes additional writing time; the use of scribes or computers when writing tests and examinations and specific academic support or adjustments in teaching and learning approaches in order to enable optimal learning and success (Lyner-Cleophas, cited in Rippenaar-Moses, 2013).

In addition, the OSSLNs role is to advocate for students with impairments and to create disability awareness on campus in collaboration with the SU Employee Wellness Office and the Centre for Inclusivity (Rippenaar-Moses, 2013). See Appendix A and B for the full SU policy document and Disability Unit's brochure.

**Table 2.2: Number of SU graduates with and without disability status: 1996 – 2012**

Disability Categories	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total degrees awarded
Blindness		2	1		3	2	2	1	1	3	4	6	3	6	3	7	4	48
Deafness			1	1	2			4	3	4	2	1	1	5	7	1	3	35
Cerebral paralysis	1	1	2			1	2	1		1		2		1	2			14
Speech disorder	1	1			1			1	1	1	4	1			2	1	5	19
Other visual disability	4	1		3	5	2	2	2	3	2	5	7	4	7	7	12	12	78
Neurological disability		1									2	1	1	2	1	2	1	11
Mobility or orthopedic disability			1	1			2	1	1	1	1	1	1	5	5	7	9	36
Diagnosed mental health disorder						1							2	3	3	4	6	19
Other disability or condition	5	1	2	5	6	6	6	10	11	16	18	21	23	17	26	18	16	207
Diagnosed reading disorder																2	1	3
Diagnosed writing disorder														1		1	4	6
Chronic health impairment							1	1		1	1		2	1	11	7	12	37
Other hearing disability					1		1		1	1		2	5	1	6	10	13	41
<b>Total graduates: disability status</b>	<b>11</b>	<b>7</b>	<b>7</b>	<b>10</b>	<b>18</b>	<b>12</b>	<b>16</b>	<b>21</b>	<b>21</b>	<b>30</b>	<b>37</b>	<b>42</b>	<b>42</b>	<b>49</b>	<b>73</b>	<b>72</b>	<b>86</b>	<b>554</b>
<b>Total graduates: no disability status</b>	<b>3774</b>	<b>3953</b>	<b>3959</b>	<b>4174</b>	<b>4710</b>	<b>4895</b>	<b>5232</b>	<b>5349</b>	<b>5351</b>	<b>5586</b>	<b>5821</b>	<b>5997</b>	<b>6198</b>	<b>6914</b>	<b>7326</b>	<b>7281</b>	<b>7757</b>	<b>94277</b>
<b>Grand total of graduates</b>	<b>3785</b>	<b>3960</b>	<b>3966</b>	<b>4184</b>	<b>4728</b>	<b>4907</b>	<b>5248</b>	<b>5370</b>	<b>5372</b>	<b>5616</b>	<b>5858</b>	<b>6039</b>	<b>6240</b>	<b>6963</b>	<b>7399</b>	<b>7353</b>	<b>7843</b>	<b>94831</b>
<b>% graduates with disability status</b>	<b>0.3</b>	<b>0.2</b>	<b>0.2</b>	<b>0.2</b>	<b>0.4</b>	<b>0.2</b>	<b>0.3</b>	<b>0.4</b>	<b>0.4</b>	<b>0.5</b>	<b>0.6</b>	<b>0.7</b>	<b>0.7</b>	<b>0.7</b>	<b>1.0</b>	<b>1.0</b>	<b>1.1</b>	<b>0.5%</b>

### 2.6.3 Literature on students with physical impairments in Higher Education

With regard to research addressing students with physical impairments in higher education, Bell (2012, p. 60) points out that less research regarding students with

impairments has been done at tertiary level in South Africa than at school level, due to the fact that the Department of Education's strategic plan was to initiate inclusion in schools first and to expand the system to tertiary institutions at a later stage.

In an attempt to address this dearth of information, the South African Council on Higher Education (CHE) launched a comprehensive study in 2003 to gain baseline data on disability from HEIs. In 2005, the CHE published their report in which they indicated the following four broad concerns:

- The ongoing impact of South Africa's historical heritage of disadvantage. Students with physical impairments continue to be viewed as unsuitable HEI material and are not prepared for the transition to HEIs.
- The role of institutional differentiation and influence of resource disparities between HEIs.
- The need for academic environments that foster flexible learning approaches. Inadequate attention is given to collaboration between disability units and faculties, as well as the training of staff, and there are often inflexible attitudes of lecturers towards changing their teaching styles to accommodate different learning styles.
- The challenge of mainstreaming support for students with physical impairments, including the separation or absence of integrated disability issues and needs.

The CHE (2005, p. 59 – 61) made the following recommendations:

- Educators' attitudinal barriers need to be addressed.
- Resource disparities between HEIs need to be reduced.
- Collaboration between disability units, support staff and academics needs to be fostered. The faculty needs to become the focal point for change and students with physical impairment needs should be integrated into the teaching and learning process.

- Disability issues need to become a part of the general processes of decision making in HEIs. Support for students with physical impairments needs to be assimilated into the core areas of the HEIs functioning.

In 2009, at the 2nd African Network on Evidence-to-Action on Disability (AfriNEAD) Symposium, Wood, Shaboodien, Kerfoot and Molteno (cited in Chataika et al., 2012) criticized the paucity of research by African institutes on youth with physical impairments in Africa. Furthermore, delegates of one of Education Commission at the 2009 2nd AfriNEAD Symposium recognized the need to do research about overlooked areas such as the sharing of success stories about students with physical impairments, and the need to present more narratives about the personal experiences of students with physical impairments in HE (Chataika et al., 2012, p. 395).

Lyner-Cleophas, et al. (2014) sum up the state of South African HEIs:

- Students with physical impairments continue to experience attitudinal, physical and institutional barriers;
- HEIs still administer disability support in a disjointed way separate from institutional transformation and diversity programmes;
- a systemic approach is required for inclusion to be successful; disability inclusion must be fully entrenched in the general functioning of the HEIs at all levels;
- students with physical impairments need to play a dynamic role;
- resilience of students with physical impairments is important but not at the expense of having to become superheroes to achieve inclusion;
- there is a need to engender values and beliefs that celebrate diversity; advocacy and community education is crucial; policy and practice needs to be improved in order to guarantee meaningful inclusion in HEIs;
- students with physical impairments' positive attitudes and self-advocacy skills are the most important indicators of success in HEIs;

- self-determination or self-belief is a means to success (p. 3)

The apparent gaps in research regarding students with physical impairments in HE and lack of full inclusion practices discussed in the preceding section indicate a need for further research to be carried out to find appropriate solutions and best practices.

## **2.7 CONCLUSION**

The following paucities within current research were highlighted in this chapter: The need for students' voices within DSE to be heard more actively; for further research with students with physical impairments in HE to be undertaken; for additional research to be carried out to provide practical solutions to narrowing the gap between inclusive policies and inclusive practices in HE; for success stories about students with physical impairments to be disseminated; and for more stories about personal experiences of disabled students in HE to be told. In addition to these needs, existing DSE research needs to be expanded by designing such research in collaboration with and by physically impaired students.

## CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

“Human beings are storying creatures”

(Sikes & Gale, 2006, p. 1)

### 3.1 INTRODUCTION

Adopting narratives as data, although a relatively new qualitative method (Clandinin & Huber, 2010; Sikes & Gale, 2006), has become increasingly more prominent as a form of inquiry into disability research (Chataika, 2005; Marks, 1999; Smith & Sparkes, 2008). This may be because narratives frequently speak a universal language, affording a common point of entrance into an experience (Hoogland & Wiebe, 2009, Qu. 8 para. 3). In addition, since narratives have the ability to engage readers, they have the potential to foster empathy towards the research participants and subsequently alter the readers' way of seeing things, and rouse them to ask new questions or to take action (Richardson, 2000, p. 937 in Hoogland & Wiebe, 2009, Qu. 8 para. 5). Chataika (2005) points out that:

it is often by telling stories that we come to understand the needs of disabled people. In the telling of life stories, previously unheard or silenced voices open up the possibility for new, even radically different narrations of life experiences. (p. 4)

As research indicates that the stories of students with physical impairments often go unheard, a life history case study approach recording the student's story is a suitable way to portray the experiences of a student with CP at a HEI.

This chapter discusses the research design and research methodology adopted in this study. As motivated above, a narrative mode of inquiry, embedded in a critical, emancipatory research paradigm, was chosen as a way to generate data. Data generating methods deemed suitable for this particular study were: existing literature, narrative interviews, analysis of Tatjana's disability poetry and additional artefacts. Interpretation of data involved a dual analysis process using both thematic and narrative analysis. This chapter includes a discussion of the ethical considerations which were adhered to in this study and mentions the important aspect of reflexivity.

### 3.2 RESEARCH DESIGN

As a point of departure for this section, the research design for the study is outlined in Figure 3.1. A research design is the research plan (Creswell, 2013, p. 49) – it defines the strategies of how one intends carrying out the inquiry (Creswell, 2014, p. 31). A research design concentrates on the end-product which is aimed at solving the research problem. Maree (2007, p. 70) explains that, “the choice of research design is based on the researcher’s assumptions and research skills,” and affects the manner in which data is generated. A researcher typically selects a research design that is consistent with the researcher’s philosophical assumptions and which is most suited to generating the type of data required to answer the research questions and solve the research problem (Finlay, 2006; Maree, 2007; Merriam, 1998). Thus, the point of departure of a research design is the research problem or question (Babbie & Mouton, 2001, p. 75). As mentioned in Chapter 1, the research problem of this study was derived from research indicating that despite inclusive policies being put in place, students with physical impairments at HEIs are not yet experiencing full inclusion and need to be consulted on decisions regarding their inclusion for meaningful transformation to occur.

Considering the limitations of a mini-thesis as a study of limited scope, the primary research question which was formulated to explore this problem was:

What was Tatjana's experience of inclusion at university?

Four sub-questions were explored in order to answer the primary research question:

1. What was Tatjana’s experience of barriers to learning at university?
2. What was Tatjana’s experience of support at university?
3. What were her personal successes while studying at university?
4. What are her recommendations to improve inclusive practices at university, especially for students with physical impairments?

Bearing in mind that a research design must be consistent with its purpose, context, paradigm and methods in order to ensure the credibility of the findings (Denzin & Lincoln,

2005, p.25), the paradigms incorporated into this study were critical theory and emancipatory research and the methodology deemed most suitable was qualitative research in the form of a participatory life history case study. The rationale for adopting these approaches for this particular study is elaborated on in the sections that follow.

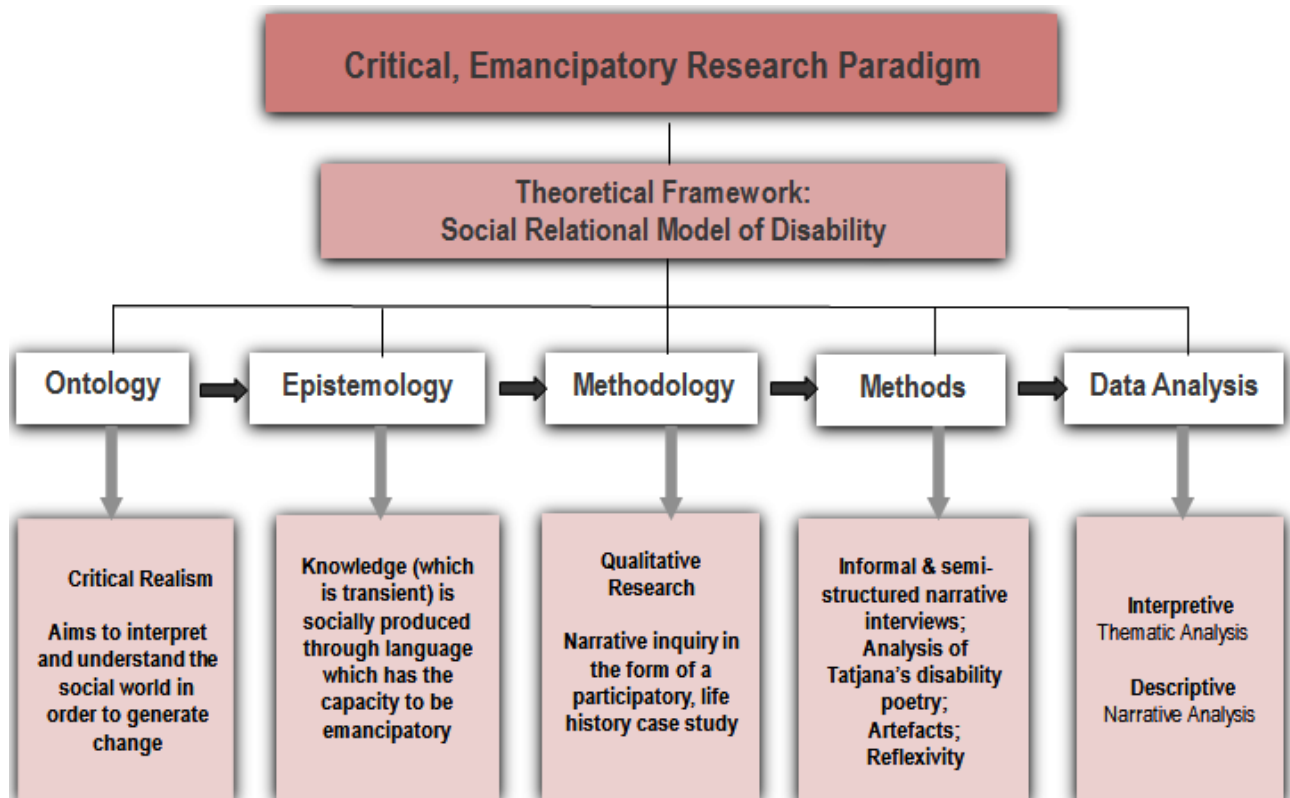


Figure 3.1: Graphic illustration of the research design of this study

### 3.2.1 Rationale for a critical, emancipatory paradigm

Mertens (2010) postulates that paradigms act as “metaphysical frameworks that guide researchers in the identification and clarification of their beliefs with regard to ethics, reality, knowledge, and methodology” (p. 469). Paradigms are, therefore, knowledge claims which infer specific assumptions about what researchers will learn during the study and how they will learn (Bloomberg & Volpe, 2008, p. 8). With this in mind, since this was a DSE study, I chose critical theory as my overarching paradigm or metatheory and emancipatory research as my methodological paradigm within the all-encompassing framework of critical theory.



### 3.2.1.1 Critical theory

In order to put critical theory into perspective, it is necessary to touch briefly on two other prominent research metatheories: the positivist and constructivist (interpretive) traditions.

Positivists have a realist view of the nature of reality and adopt objective epistemologies, applying rigorously delineated quantitative methodologies such as surveys (Denzin & Lincoln, 2005, p. 24). This paradigm was not adopted in this study, as the *subjective* life experience of a student with CP was the topic under investigation. A certain amount of methodological flexibility was thus required.

Constructivists (as opposed to positivists) embrace the notion of multiple realities, adopt subjective epistemologies where understandings are co-created and use naturalistic methodological techniques such as ethnographies and interpretive case studies (Denzin & Lincoln, 2005, p. 24). Mertens (2010, p. 470) points out that more recently the element of social justice has been added to the belief systems of the constructivist paradigm. She explains that researchers can, however, still position themselves within the constructivist paradigm and not focus on concerns of social justice.

Critical theory, however, is entrenched in the principles of social justice. Brookfield (2005 cited in Bloomberg & Volpe, 2008) explains that critical theorists see research as interwoven with politics. Critical theorists therefore promote research that will bring about change in the participants' lives as well as the researcher's life (Creswell, 2013, p. 26). Also known as an advocacy paradigm (Bloomberg & Volpe, 2008, p. 9), critical theory includes disability inquiry, amongst others. Research approaches such as participatory action research and narrative analysis are classically used, both of which have empowering objectives. Bloomberg and Volpe (2008) explain that:

It is assumed that the (critical) researcher will engage participants as active collaborators in the inquiry so as not to further marginalize them as a result of the inquiry. Participants are typically involved in designing questions, collecting data, and analysing and interpreting information...so that their voice can be heard and their consciousness can be raised. (p. 9)

I regard this critical theory stance as a good fit for this study. I had not merely sought to undertake a basic interpretive qualitative study. In the basic interpretive qualitative approach, the focus is on “understanding how participants make meaning of a situation or phenomenon, this meaning is mediated through the researcher as instrument ... and the outcome is descriptive” (Merriam, 2002, p. 6). I wanted to go further than a basic inquiry. Although the basic interpretive paradigm has merit for many studies, since this was a DSE I was determined to include the research participant in a more empowering role. This notion is supported by Mertens, Sullivan and Stace (2011, p. 229) who comment on Oliver’s criticism of the interpretive paradigm as “not going far enough as it does not change the relationship between the researcher and the researched/disabled” (Mertens, Sullivan & Stace, 2011, p. 229). Disabled participants in interpretive studies are often left feeling estranged. In my opinion, Oliver has developed a more apt methodological paradigm for disability research - the emancipatory paradigm - which has been adopted in this study and which is elaborated on in the next section.

### **3.2.1.2 Emancipatory research**

Emancipatory research “seeks to advance the interests of ‘subordinate’ or oppressed groups in society” (Guba, 1990, p. 47). For research to be viewed as emancipatory, Mertens, et al., (2011) contend that it should have the following characteristics:

- Emancipatory research aims to expose and change disabling social structures in order to expand the control people with impairments have over their own lives.
- Emancipatory researchers make their skills available to people with physical impairments, thereby rectifying the skewed power relationship between the researcher and the disabled participants.
- People with disability control the research process. They can determine the ‘what, the how, and the when’ of the process.
- Emancipatory research concentrates on the strengths and coping skills of disabled people, rather than on their weaknesses.

- Emancipatory researchers carry out research that studies the contextual and environmental factors that either enable or hinder a person with a disability in assimilating into society (p. 229).

These characteristics are well suited to this DSE, as the purpose of this study is to encourage further change regarding the inclusion and support of students with physical impairments at HEIs, by involving Tatjana as co-researcher of this study and gaining first-hand knowledge from her as a student with CP. Furthermore, in line with DS, the intention was to promote Tatjana's self-empowerment. My role then as a critical researcher was to support her on her own journey of self-discovery (Tregaskis, 2004, p. 2).

### **3.2.2. Purpose of the study**

As indicated above, this research hopes to improve the support of current and future students who have physical impairments at SU and other similar institutions, through creating awareness amongst the university's role players of the need for improvement, by sharing Tatjana's story and the subsequent formulation of recommendations for improvement. The intention of this study was for students with physical impairments to benefit from the research outcomes. However, my aim is not to generalise findings but to contextualise the findings according to this study's foci and setting.

This study also hopes to self-empower the research participant/co-researcher, Tatjana, by giving her the opportunity to share her story – for her voice to be heard and in turn have the potential to empower others.

### **3.2.3. Context of the study**

A context is “a culturally and historically situated place and time” (Graue & Walsh, 1998, p. 9), framing a situation in a specific way. It is essential to situate the context of a study (Bloomberg & Volpe, 2008) as it refers to the “larger field of relevant factors, relationships and structures in which the case is located” (Rule & John, 2011, p. 40). Contextual information is particularly important if the case study is set in a specific location, as elements within the environment or culture may affect behaviour (Lewin, 1935 cited in Bloomberg & Volpe, 2008, p. 70). Although the unit of analysis or case of this study was

Tatjana, a student with CP, the embedded units of analysis within the case, as well as the contextual influences, contributed to an understanding of the case (Rule & John, 2011).

This study took place in Stellenbosch, South Africa on the SU campus. SU was established as such in 1918 but its roots date back as far as the 17<sup>th</sup> century. It is historically a predominantly White, Afrikaans-medium institution - an Historically Advantaged Institution (HAI). SU is currently one of the top-ranking South African public research universities, with a student corps of 28 000 and a lecturing staff of 939 (SU website 2016).

With the end of apartheid in South Africa in 1994, new national non-discriminatory policies were formulated which not only had implications for generically black student access to HE but also created the opportunity for largely previously excluded students with impairments to gain access to HE. The latter had repercussions with regard to South African universities' readiness to accommodate students with impairments, including SU. National policies were in place but practices needed to be established. Environments, curricula and mind-sets needed to be changed. SU therefore appointed an ad hoc committee in 1994 to review the inclusion of students with physical impairments on campus (Rossouw, 2005 cited in SU, 2013, p. 226). Subsequently, the Advice Forum for Students with Disabilities was established in 1997 and since 2006 the services for SU students with physical impairments have fallen under the Centre for Student Counselling and Development (CSCD), the point of specific service being the Office for Students with Special Learning Needs/Disabilities (OSSLN).

### **3.2.4 Rationale for qualitative research methodology**

Generally, qualitative research seeks to explore and understand a specific phenomenon from the insider's point of view (Babbie & Mouton, 2001, p. 53). It is "an inquiry process of understanding ... [where] a researcher builds a complex, holistic picture, analyzes words, reports detailed views of participants, and carries out the study in a natural setting" (Creswell, 2007, p. 249). Finlay (2006) emphasizes that "a qualitative study should be judged on its ability to draw the reader into the researcher's discoveries, allowing the reader to see the worlds of others in new and deeper ways" (p. 322). According to Denzin and Lincoln (2005, p. 7), a qualitative researcher often considers reality from a

constructivist stance, which includes “multiple meanings of individual experiences”. In addition to this stance, an advocacy or participatory perspective is sometimes incorporated to aid the promotion of social justice for persons marginalised by society (Mertens, 2003 cited in Maree, 2007), as was done in this study.

Quantitative research methodology, which is characterized by the quantification of constructs (Babbie & Mouton, 2001, p. 49) and objective universal truths (Rule & John, 2011), was not considered for this study, as the aim was to record *one* student with CP’s *subjective* experience of learning and support. The individual story was important to this study. Qualitative methodology was, therefore, used to investigate the thesis topic through a narrative inquiry in the form of a participatory life history case study.

#### **3.2.4.1 Rationale for case study methodology**

Creswell (2013, p. 97) describes case study research as a qualitative approach “where the (researcher investigates) a bounded system (a case or unit of analysis) over a period of time, through detailed, in-depth” gathering of data, incorporating various sources of information, then reporting a case description and case-centred themes. It can be further described as an empirical inquiry that “investigates a contemporary phenomenon (‘the case’) in its real world context” (Yin, 2014, p. 2).

The type of case study chosen for this mini-thesis from the various types of case studies available was a life history case study. With this type of case study (also known as life stories, biographical case studies, personal experience stories, portraitures and life-world methodology) the researcher typically carries out rigorous interviews with one individual for the purpose of formulating a first-person narrative (Merriam, 2009, p. 48).

I perceived life history case study methodology to be well suited to this study, as it allowed Tatjana’s experience to be explored in depth through listening to and recording her individual story, as opposed to looking at a number of students with physical impairments’ experiences in less depth (Rule & John, 2011). The aim of this research was an intensive rather than an extensive inquiry, as the focus was on one student with CP (Tatjana) studying at Stellenbosch University. Furthermore, Hodge (2008) claims that because life-world methodology gives comprehensive reports of individual experience, it is well positioned to “enable the richness of the diversity within the disabled community to be fully

explored” (p. 38). Frank (1995 cited in Reindal, 2008) too highlights the importance of recording the individual experience of living with a physical impairment and how it has the capacity to enrich and be a source of empowerment to others, by giving the experience a voice. I therefore chose this methodology according to the principle of “fit for purpose” (Rule & John, 2011, p. 8). In addition, the “singularity of focus” (Rule & John, 2011, p. 8) of a life history case study made this study more manageable than a large-scale survey, for example, since this was a mini-thesis with certain time and volume constraints.

Within the context of a DSE, this case study also incorporates participatory research elements, as Tatjana was viewed as a partner throughout the process. This aspect is in line with the overall paradigm of this study, as according to Merriam (2009), participatory research draws on critical theory. This concept is elaborated on in the next section.

### **3.2.5 Selection of participant / co-researcher**

Purposive sampling, which entails the deliberate selection of the research participants because of their suitability in advancing the research purpose (Rule & John, 2011, p. 64) and answering the research questions, was employed in this study. As qualitative research aims to study the meaning of a phenomenon from the participants’ angle, it was important to choose a sample for this study from which most could be learned (Merriam, 2002, p. 12). Since qualitative researchers (as opposed to quantitative researchers) generally work with non-probability, non-random samples (Durrheim & Painter, 1999, p.139; Merriam, 1998, p. 61), the use of purposive sampling in this study was considered to be appropriate.

Patton (1990 cited in Merriam, 2002, p. 12) contends that when employing purposive sampling it is important to select “information rich” cases for in-depth study. With this in mind, Tatjana was selected as a participant and co-researcher as she met the specific criteria of this inquiry – she was a student at a HEI with a physical impairment: CP. By the end of 2012, on completion of her studies, she had 6 years of experience to share. Table 3.1 provides a summary of Tatjana’s biographical data.

As mentioned earlier, Tatjana was viewed as a partner or co-researcher during the research process. I was aware of Ostrove and Rinaldi’s (2011) emphasis on the responsibility we as non-disabled researchers have to position ourselves in relation to our research in DS. Ostrove and Rinaldi (2011) recall the Disability Movement’s slogan

“nothing about us without us”. I took cognizance of this and endeavoured to treat Tatjana as my equal throughout this inquiry (see Appendix E as an example), affording her the “power of veto” (Tregaskis, 2004, p.2) over the choice of inclusion of data in the final product. However, as the primary researcher I ultimately integrated, structured and interpreted Tatjana’s story by referring to the literature.

### 3.3 ETHICAL CONSIDERATIONS

Researchers are ethically required to carry out research in a way that minimises possible injury to the people concerned in the research (Bloomberg & Volpe, 2008, p. 76). Furthermore, Rule and John (2011, p. 111) point out that carrying out research in a morally correct way improves the research quality and adds to its credibility. Ethical issues were, therefore, monitored throughout the entire research process of this study, as I was aware that they had the potential to occur in any one of the research phases (Bloomberg & Volpe, 2008).

According to the *Singapore Statement on Research Integrity* (2nd World Conference on Research Integrity, 2010), there are four main principles that are central to the integrity of research. Guided by these principles, I endeavoured to be honest in all facets of this research study; to be accountable in the conduct of my research; to show professional courtesy and fairness in working with others; and to demonstrate competent stewardship of research in the best interests of others (2nd World Conference on Research Integrity, 2010). Since this was a critical disability study, particular care was taken to ensure that all parties impacted by this study were regarded. This aspect links up with Finlay’s (2006) fifth “C” dimension of *Caring* discussed in point 3.6.3 of this chapter.

Institutional permission to do research with a student at SU was requested and granted (see Appendices C and D). In addition to institutional permission, ethics clearance to conduct the research was granted by the university’s Research Ethics Committee (REC) (see Appendix H). All of the stipulations and conditions stated in the latter documents were adhered to and respected.

**Table 3.1: Tatjana's biographical data in 2012**

<b>Participant</b>	<b>Age</b>	<b>Gender</b>	<b>Year of study<sup>11</sup></b>	<b>Onset of CP</b>	<b>Classification</b>	<b>Assistive devices</b>	<b>First language</b>	<b>Second language</b>	<b>Residence</b>
Tatjana	26	Female	Final	Pre-birth	Spastic quadriplegia	Crutches Mobility 'scooter'	German	English	University residence

Regarding the important aspect of participant confidentiality, as this was a critical disability study, Tatjana was viewed as a co-researcher. As an adult participant eager to act as an advocate for change, she indicated from the start that she did not want to use a pseudonym. Tatjana waived her right to confidentiality. Although the reasons for remaining anonymous (to protect her identity; to protect her from possible victimization) were explained to her, she did not see herself as vulnerable and in need of protection. Her letter to the REC is attached as Appendix F and succinctly sums up how she felt about the matter.

As far as the potential risks of the study were concerned, I was cognizant that this research process had not only the potential to be emancipatory in nature for Tatjana, but also the potential to unsettle her, as she might recall situations that might evoke uncomfortable memories (Hodge, 2008, p. 32). The sharing of personal life experiences, therefore, had the potential to expose sensitive matters (Chataika, 2005, p. 8). I was mindful of these aspects throughout the inquiry, reflexively monitoring the process with sensitivity. An open relationship as co-researchers had been fostered and back-up therapeutic support measures were in place should any issues have arisen.

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<sup>11</sup> Year of study at the time of the interviews



Since, Warin (2011) contends that “reflexivity and ethical mindfulness are interdependent concepts” (p. 805), a discussion on reflexivity follows in the next section.

### **3.4. REFLEXIVITY**

“Reflexivity” refers to the researcher being critically self-aware throughout the research process (Finlay, 2006, p. 319). It is a move away from “a focus on data collected to the internal dialogue of researchers that helps them [to] understand what is known and how it is known” (Berg, 2009; Finlay, 2012; Patton, 2002 cited in Valandra, 2012, p. 204).

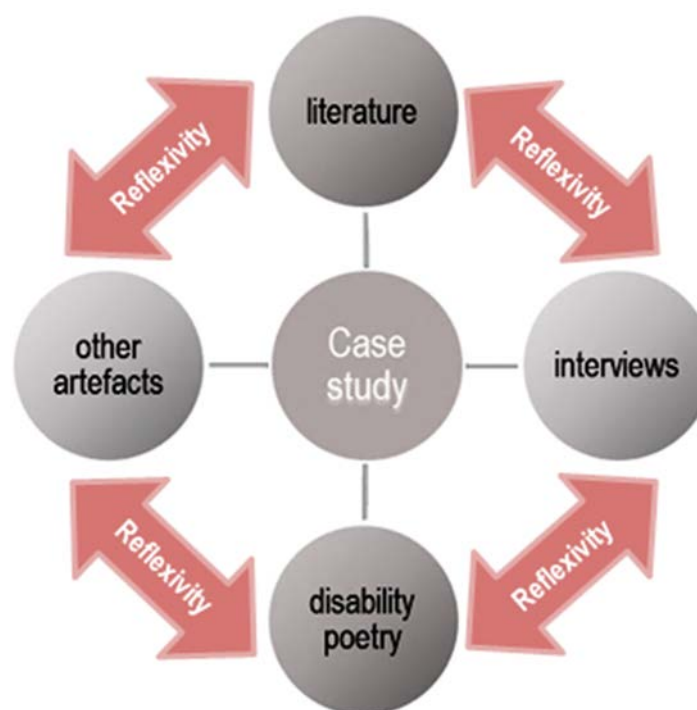
Reflexivity is about introspection for some and to others it is a methodological tool for “shaping, adapting, or otherwise responding to the research process with intention and purpose as the study unfolds” (Stronach, Garratt, Pearce, & Piper, 2007; Underwood, Satterthwait, & Bartlett, 2010 cited in Valandra, 2012, p. 204). In addition, reflexivity can be a way for researchers to “come clean” (Valandra, 2012, p. 204) about their research process by addressing the power relations between the interviewer and interviewees, for example. As such, reflexivity in DS plays a vital role. Rinaldi (2012) asserts that “Disability studies calls for at least a reflexive (if not a disabled) researcher, one who reflects upon how perspective and privilege affect knowledge” (para. 1).

Denzin and Lincoln (1998), Finlay (2006), and Valandra (2012), amongst others, also claim that reflexivity plays a crucial part in strengthening the credibility and trustworthiness of qualitative research and that the researcher’s role must be explicitly acknowledged and accounted for in the research documentation. My self-reflections are, therefore evident throughout this study.

### **3.5 DATA COLLECTION**

To answer the research questions of this inquiry adequately, data were gathered by means of five methods: 1) The literature review; 2) four narrative interviews; 3) Tatjana’s disability poetry; 4) additional support artefacts and 5) researcher reflexivity.

The visual representation of the data collection process of this study is presented in Figure 3.2.



*Figure 3.2: Graphic illustration of the data collection process of this study*

The use of multiple methods of data collection (also known as triangulation) in this study was important as this helped to form an in-depth understanding of Tatjana's experience. This approach adds rigour, breadth and depth to an inquiry, providing corroborative evidence of the data gathered (Yin, 2014, p.119). Van der Mescht (2002 cited in Rule & John, 2011, p. 109), however, disagrees with the latter claim. He admits that multiple sources may give a fuller picture but not necessarily a more accurate one. Rule and John (2011, p.109) suggest the use of data saturation as being an additional method to implement to ensure that a more accurate picture is achieved. Thus, multiple methods of data collection and data saturation were used in this inquiry.

As Merriam (1998, p. 137) indicates, when using multiple methods of data in a study, one or two data gathering methods usually predominate, while the other methods take on a supporting role, adding to the depth of understanding of the case. In this study, interviewing and the analysis of Tatjana's disability poetry were the dominant methods of data collection and the additional artefacts described in 3.5.4 of this chapter served as secondary but important corroborating sources of data.

During this phase of the research, I was cognizant that data collection and data analysis should not be viewed as two separate processes but as “an ongoing, cyclical and non-linear process” (Nieuwenhuis, 2007, p. 81). I was also aware that clarity on process and practice of method was crucial for the reader to be able to evaluate the research properly (Braun & Clarke, 2006, p. 80).

### **3.5.1 Existing literature**

According to Merriam (1998), a study’s literature review is “a narrative essay that integrates, synthesizes and critiques the important thinking and research on a particular topic” (p. 55). A selective and thorough literature review was carried out over a lengthy period prior to, during and after the data collection process of this study. This review was ongoing, generating new information and supportive evidence related to this study (Bloomberg & Volpe, 2008). Literature was obtained from various sources, including academic books, journal articles, policies, legislation and the Internet. More specifically, international and national developments and policies regarding inclusion and inclusive education were reviewed; theories and models of disability were discussed in order to develop an appropriate theoretical framework for this study; and the prevalence of research carried out on or with students with physical impairments in HE at international and national levels was explored in order to highlight the apparent gap in research regarding these students; therefore, demonstrating a need for this study. The theoretical framework formulated in my literature review was used to guide my data collection, data analysis and findings of this study. Following the literature review, four informal, semi-structured narrative interviews were conducted with the participant, Tatjana, as discussed in the following section.

### **3.5.2 Informal and semi-structured interviews**

Interviews, which are often the main source of data collection in qualitative research (Bloomberg & Volpe, 2008; Merriam, 1998), due to their ability to provide in-depth information concerning the participants’ experiences and to zoom in on the case study topic specifically (Yin, 2003), were conducted in this study.

There are a variety of interview designs which can be used to get thick, rich data. In Turner’s 2010 article, he describes three general formats of interview design for novice

researchers. These formats are the informal conversational interview, the general interview guide approach and the standardized open-ended interview (p. 754). I adopted a combination of the first two formats to guide me in my interviewing and also incorporated storytelling as a variation of the typical interview (Rule & John, 2011, p. 65). Storytelling entails encouraging research participants to tell their life story or to elaborate on a specific experience (Rule & John, 2011, p. 65). According to Rule and John (2011), the benefit of using storytelling as an interview approach is that it allows the participant(s) freedom over the data generated in an “informal, non-directive and non-threatening” (p. 65) way. This method proved to be effective in this study.

In order to establish a good interviewing “space” which would be conducive to gaining in-depth accounts of Tatjana’s experiences at her university, I undertook to transform the typical interviewee-interviewer relationship into one of narrator and listener (Chase, 2011, p. 423), and followed Rule and John’s (2011) interview guidelines: 1) I created a relaxed atmosphere; 2) I went through the nature and the purpose of the research with Tatjana again; 3) I encouraged Tatjana to ask questions to clarify aspects of the study and confirmed her willingness to go ahead with the interviews before the interviews began (at this stage she signed the participant consent form - see Appendix G) and throughout the interview process; 4) I reminded Tatjana of my ethical obligations; 5) I used a conversational rather than an inquisitorial style; 6) I endeavoured to listen attentively and to avoid interrupting Tatjana; 7) I aimed to be respectful and sensitive to the emotional climate of the interviews; 8) and I probed when necessary and summarized my understanding at certain intervals (p. 64).

Since the interview is a relational encounter where both parties are mutually influenced by one another (Holstein & Gubrium, 1995 cited in Vincent, 2013, p. 343), I was aware of my position as non-disabled researcher, 17 years Tatjana’s senior and an administrative employee of the university as well as the impact this might have on our relationship and ultimately on the findings of the study (Vincent, 2013, p. 343). The decision to adopt a co-researcher approach in this study in order to foster a more collaborative, less hierarchical relationship (Oakley, 2002 cited in Vincent, 2013, p. 344) helped to alleviate these concerns. I also referred back to my research journal regularly to reduce “researcher

effects” (Burton, 2010, p. 317) and to consider the power relationship factor at regular intervals.

Prior to the first interview, a semi-structured interview guide was formulated (See Appendix I). The initial purpose of this interview guide was to encourage more flexible, open-ended responses from Tatjana. However, many of the prompts that I had included in my interview guide were unnecessary in the end, as Tatjana required very little prompting and was eager to share detailed phases of her lived experiences spontaneously. Chase (2011, p. 423) indicates that this is sometimes the case and that interview guides may or may not be needed when following the narrator’s story. So, as an alternative to my original interview guide, I adapted my approach accordingly and followed my intuitive promptings (Smith-Chandler, 2011, p. 61) based on the flow of the conversation.

Four informal semi-structured conversational narrative interviews with Tatjana were conducted in English (Tatjana’s choice of language for the interview) over a two-month period. The individual interviews were carried out at times and places that were chosen by Tatjana. On completion of the first interview, Tatjana confessed that she was sore after sitting on the floor for such a long period. We had worked on the time-line on the floor as it provided a bigger surface. This was a learning curve for me and highlighted the importance of ascertaining and negotiating suitable interviewing conditions with the interviewee prior to carrying out an interview. The next interview was conducted with Tatjana seated on a couch and the last two interviews were conducted at a counter, which proved to be much better options for Tatjana.

The initial interview (which lasted 2 hours) covered Tatjana’s story from pre-birth till 2007 (her first year at university). A time-line illustrating Tatjana’s life story was used as a point of departure that was elaborated on during the subsequent interviews (see Appendix I). The second interview (which lasted 1 ¼ hours) fed into the first interview’s conversation and focused on Tatjana’s university experience over the period 2007 – 2012. Tatjana was asked to reflect on her poetry during the third interview (2 ¾ hours in length), to tell the story behind her poems. During the last interview (which lasted ½ hour), follow-up questions or probes (Merriam, 1998, p. 93) were used to fill in the gaps in Tatjana’s story, recapping and adding events that happened during 2011 and 2012. The benefits of these repeat interviews (Vincent, 2013), as opposed to the once off single interview, were that I

was able to gather a good deal of data to meet the aim of data saturation, thus “providing thick descriptions and holistic understandings” (Vincent, 2013, p. 342) of Tatjana’s experiences. In addition, a positive relationship between Tatjana and me was fostered through these repeated contacts, allowing for ease of conversation. Vincent (2013) asserts that repeat interviews are “particularly appropriate when dealing with sensitive issues or vulnerable populations and when gaining authentic accounts requiring a high degree of trust between the researcher and the participants” (p. 343).

The interviews were recorded with a digital audio recorder, with permission granted by Tatjana, and later transcribed carefully, taking cognisance of the importance of recording the responses accurately in order to avoid bias (Yin, 2003, p. 86) and to reflect Tatjana’s intended meaning. In addition, electronic copies of the transcriptions were sent to Tatjana for her to verify their accuracy. My self-reflections were recorded after each interview so as not to miss any of my own personal experiences during the process.

### **3.5.3 Poetry as data**

The value of using poetry as data lies in its ability to provide deep insights into the lived experiences of individuals (Furman, 2007; Richardson, 1993). This is because poems have the capacity to clarify and magnify existence (Hirshfield, 1997 cited in Furman, 2007) and to convey strong emotion. Furman (2007) likens poetry to “an emotional microchip”, in the sense that it may act as a “compact repository for emotionally charged experiences” (p. 1 para. 3).

Poetry has been utilized in research in a number of ways. Firstly, poetry as a qualitative methodological instrument, although somewhat controversial, has become increasingly more prevalent in qualitative research (Finlay, 2006; Furman, 2004, 2006, 2007; Furman, Langer & Taylor, 2010; Richardson, 1993; Shapiro, 2004; Willis, 2002a). Here research poems are used as a method of inquiry and as a method of representing data (Furman, 2006). Secondly, poetry can be seen as a kind of therapeutic process for the participant, which if utilized in research can also be viewed as specific pieces of evidence or information (Shapiro, 2004, p. 171), as was the case in this study. During my interactions with Tatjana, I discovered that she is a prolific poet. It became evident upon reading her poetry that her poems were telling her story. A number of her poems narrate her life-world

of being disabled and would be viewed in literature as ‘disability poetry’ (Wordgathering, 2008) or ‘crip poetry’ (Ferris, 2008). These poems, which were originally written for her personal therapeutic and creative purposes, were incorporated as raw data for discussion and analysis in this study. Tatjana willingly shared her poems and helped to select relevant poems. They became important sources of data as they produced repeated themes and proved to be rich in imagery and emotive language, adding a particular depth to this inquiry.

### **3.5.4 Additional artefacts**

Tatjana's journal extracts, extracts from previous letters and emails to lecturers and support staff, photographic evidence generated by me and my own personal research journal notes were used as additional supporting data.

Regarding the confidentiality of third parties, care was taken to keep references to personnel and departments anonymous and any other possible identifiers in the data were removed.

## **3.6 DATA MANAGEMENT AND ANALYSIS**

Data management is the process whereby the data from the recorded interviews is transcribed into text. The 6 ½ hours of recorded data were carefully transcribed over a period of 3 weeks. Once the transcriptions were complete, they were thoroughly checked against the original recordings for accuracy. Pauses, emphases, and phrasing were also cross-checked by me and Tatjana. The latter aspects were especially important for the narrative analysis phase. Once the interview transcriptions had been “cleaned” (Rule & John, 2011, p. 77), in order to immerse myself in the data (Burton, 2010, p. 317) I read and re-read the transcriptions numerous times before starting the analytic process (see Appendix J). I applied two forms of data analysis - narrative analysis and thematic analysis – in order to examine and report Tatjana’s storied accounts of her experience as a student with CP at a HEI. By incorporating dual analysis, I sought to expand the richness of the data to ensure comprehensive findings. See Figure 3.3 for a graphic representation of the data analysis process of this study.

### 3.6.1 Narrative analysis

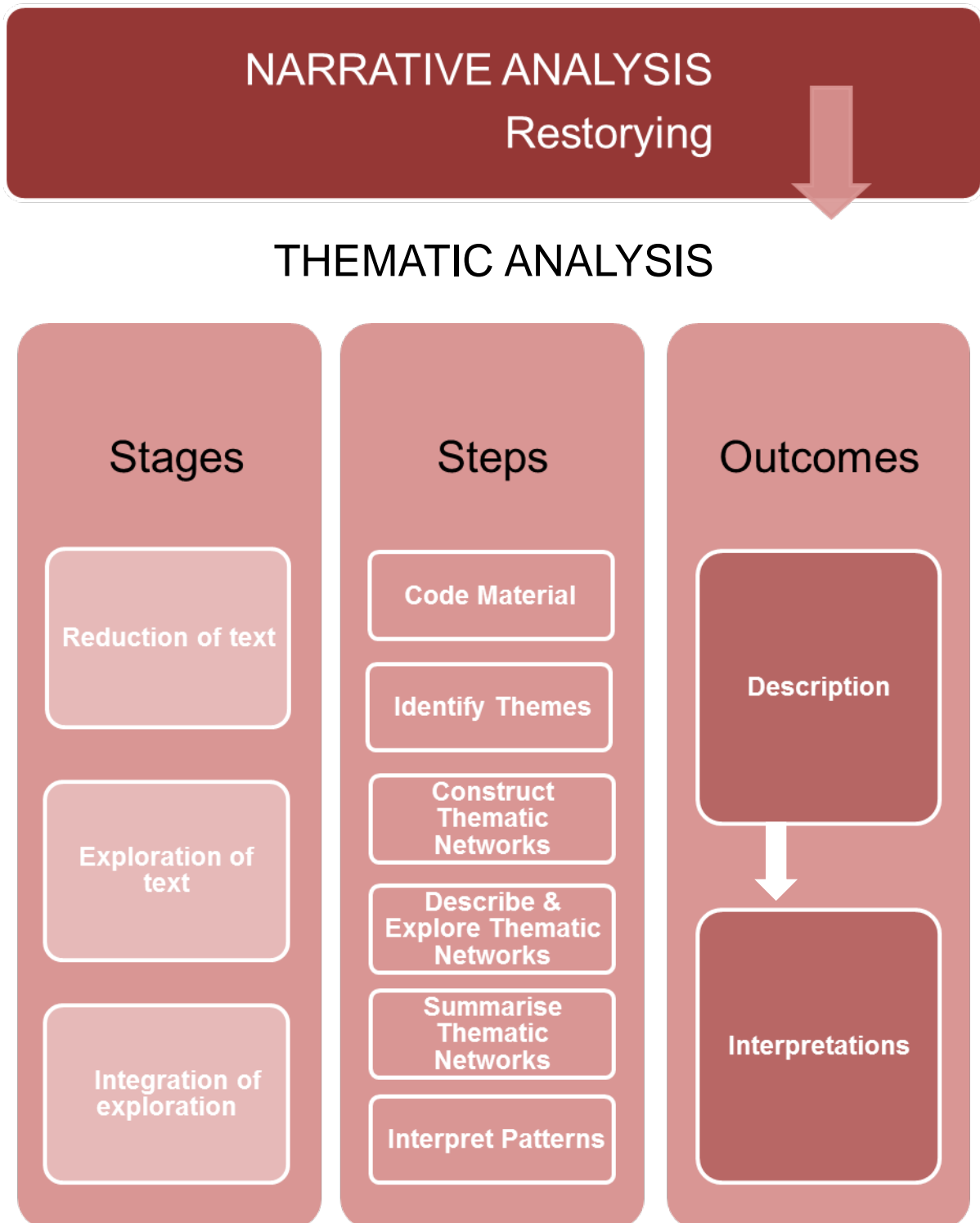


Figure 3.3: Graphic representation of the data analysis process of this study, incorporating Creswell's (2013) restorying of narrative analysis and Attride-Stirling's (2001) stages of thematic analysis.



According to Rule and John (2011, p. 80), narrative analysis is suitable for data generated from in-depth life history interviews that incorporate storytelling methods, as was the approach in this study.

Narrative analysis as a generic term is a method that focuses on the story itself as its object of analysis (Riessman, 1993 cited in Smith & Sparkes, 2008, p. 19). The researcher who undertakes narrative analysis generally accepts that language expresses meaning and that the way (the “how”) in which a story is narrated is as important as the content (the “what”) of the story (Esterberg, 2002 cited in Smith & Sparkes, 2008, p. 20). Furthermore, narrative research is inclined towards studying the subjective experiences of the narrator and contextual situations within the story, focusing on the manner in which events are causally linked and accorded meaning by their connections. The story is normally temporally and spatially situated (Sikes & Gale, 2006, p. 16).

There is a variety of narrative analytical techniques, varying from a story analyst approach to a storyteller approach (Smith & Sparkes, 2008, p. 19). As a novice researcher, I chose to keep my approach fairly simple. I chose narrative analysis, which focused on identifying and interpreting the significant *story markers* (Rule & John, 2011, p. 80) within Tatjana’s story. The emphasis during this phase of analysis was more on the language structure of her story than on the content of the story.

Thus, before the thematic analysis phase was done, I embarked on the process of “restorying”. Restorying involved rearranging Tatjana’s story chronologically into a general framework (Creswell, 2013, p. 74). I, therefore, considered how Tatjana’s story was structured from beginning to end; I reflected on how her story unfolded with regard to time, setting, and plot, pinpointing subtle shifts in Tatjana’s story, her pivotal life events, and noticeable omissions in her story, as well as verbalized personal epiphanies (Johnson-Bailey, 2002, p. 324); I studied how her story was linked to its immediate and broader contexts; I identified the protagonists and antagonists; I looked at how Tatjana positioned herself in her story and how her descriptions of actions and conflict were imparted; I looked for principle identifiers of salience (Alexander, 1988, p. 268), such as recurrences and emphases; and I took note of whose voices were fore-grounded in her story and whose voices were missing (Rule & John, 2011, p. 80).

The final product of the narrative analysis was thus Tatjana's story unfolding in a chronology of her experiences positioned within her personal, social and historical context, incorporating the salient themes of her lived experiences (Creswell, 2013, p. 75). Once again, my reflexivity towards my own personal background was vital, as my life experiences, too, would shape how Tatjana's story was restored.

As stories are the means by which people communicate and the mode in which we make sense of our lives, it was crucial that the gist of Tatjana's original meaning was maintained, that her voice was preserved (Johnson-Bailey, 2002, p. 324). Therefore, as with the thematic analysis phase of data analysis, upon completion of this phase of analysis I asked Tatjana to review my analysis of her narrative and to comment on my interpretations. In a sense, this was a process of negotiating the meaning between both parties (Creswell, 2013, p. 75) to address the important question of "Who owns the story?" (Pinnegar & Danes, 2006 cited in Creswell, 2007, p. 57).

### **3.6.2 Thematic analysis**

Attride-Stirling (2001) is of the opinion that, "If qualitative research is to yield meaningful and useful results, it is imperative that the material under scrutiny [be] analysed in a methodical manner" (p. 387). Thematic analysis was therefore utilized as an additional method in order to support the narrative analysis carried out in the first phase of data analysis of this study.

Thematic analysis is a method of identifying, analysing and reporting patterns or themes within data. This approach organizes and describes the data in vivid detail. It often goes a step further and also interprets facets of the research inquiry (Boyatzis, 1998 cited in Braun & Clarke, 2006, p. 79). I adopted "thematic networks" as a tool for my thematic analysis, guided by Attride-Stirling's (2001) proposal that thematic networks are a useful aid for thematic analysis. Thematic networks are "web-like" visuals that encapsulate the main themes of a text. Thematic analysis strives to reveal the salient themes in data on various levels, with the intention of mobilising networks to facilitate the organization and depiction of these themes (Attride-Stirling, 2001, p. 387). Attride-Stirling (2001) views the thematic network technique as a "robust and highly sensitive tool for the systematization and presentation of qualitative analyses" (p. 385). As a novice researcher, I found this

approach very useful and structured my thematic analysis according to Attride-Stirling's (2001, p. 391) suggested steps in thematic analysis:

### **Analysis stage A: Reduction or breakdown of text**

#### *Step 1: Coding the material (see Appendix K)*

This step entailed devising a coding framework (founded on prominent issues that were evident in the data set, guided by my research questions) and then breaking down the text into text segments using the coding framework devised. This was done in order to reduce the text to text segments, which included identifying "meaningful and manageable chunks" (Attride-Stirling, 2001, p. 391), such as paragraphs, quotations, and specific words.

I was cognizant that this initial step of coding needed to be done rigorously, with specific attention to detail (Attride-Stirling, 2001, p. 391) and that the codes in my coding framework needed to be delineated clearly to avoid redundant coding. My subjective impressions from my research journal were also reflected on at this initial stage. Some of my initial hunches were accurate and supported the findings, while others were found to be biased assumptions and were removed from the data (Burton, 2010, p. 317).

#### *Step 2: Identifying the themes (see Appendix L)*

The next step involved identifying abstract themes from the coded text segments and then refining the themes. I went through the text segments in each code and took out the obvious, common and important themes. I then refined the themes further so that they were specific enough to be non-repetitive and broad enough to summarize a group of ideas found in numerous sections of the text (Attride-Stirling, 2001, p. 392). This involved meticulous interpretive work as the relevant texts needed to be re-presented accurately and concisely (Attride-Stirling, 2001, p. 392).

#### *Step 3: Constructing the thematic networks (see Appendix M)*

During this step, the themes identified during the previous step were used as a source for the thematic networks. The themes were arranged: first the *basic themes* were selected and then rearranged into *organizing themes* from which *global themes* were ultimately deduced. These themes (the basic, organizing and global themes) were then illustrated as

“non-hierarchical, web-like representations” (Attride-Stirling, 2001, p. 393), with each global theme generating a thematic network. Once this was done, I verified and refined the networks further by going through the text segments again to make sure that the themes identified reflected the data accurately and that the data in turn supported the themes (Attride-Stirling, 2001, p. 393).

### **Analysis stage B: Exploration of text**

#### *Step 4: Describing and exploring the thematic networks*

The networks were described and explored during this step. As Attride-Stirling (2001) explains, the thematic networks are merely a tool in the analysis process. After the networks were composed, the original text needed to be revisited and interpreted, aided by the networks. Each networks' contents were described and substantiated by text extracts. Underlying patterns became evident and were noted during this process, too.

#### *Step 5: Summarizing the thematic networks*

According to Attride-Stirling (2001), this step is important as the main themes and patterns are presented “succinctly and explicitly” to the reader, which makes the “interpretation more compelling” (p. 394).

### **Analysis stage C: Integration of exploration**

#### *Step 6: Interpreting patterns*

This last step required me to go back to the initial research questions and theoretical framework, framing the research questions in order to address them with arguments based on the patterns that were discovered during the exploration of the texts (Attride-Stirling, 2001, p. 394).

Once this process was complete, Tatjana was asked to review my analysis of her story and to comment on its accuracy to enhance the credibility of the findings.

### **3.6.3 Research criteria of the study**

Although it became evident to me during the research process that there are a variety of evaluative criteria available to qualitative researchers, I discovered that there appears to be a general consensus within the qualitative world that *trustworthiness*, *rigour*, and *relevance* remain the common important evaluative denominators (Finlay, 2006, p. 323).

Guba and Lincoln (1998 cited in Bloomberg & Volpe, 2008) consider that the *credibility*, *transferability*, *dependability* and *confirmability* of an inquiry establishes its trustworthiness (p. 85). These terms, which are regarded by many qualitative researchers as terms that are better suited to the nature of qualitative inquiry, replace the traditional quantitative terms of internal validity, external validity, reliability and objectivity (Bloomberg & Volpe, 2008; Finlay, 2006). Ways to ensure credibility in qualitative research, and which were incorporated into this study, are to be upfront and reflexive about one's potential researcher biases (Bloomberg & Volpe, 2008, p. 77); to gather multiple sources of data and to use triangulation (Rule & John, 2011, p. 109); to use "member checks" (Finlay, 2006, p. 321) thereby verifying the transcriptions and findings with the participant(s); to point out contradictory findings (Bloomberg & Volpe, 2008, p. 77); and to use critical peers or one's research supervisor to check one's data or to play devil's advocate regarding one's assumptions or ways of seeing the data (Bloomberg & Volpe, 2008, pp. 77 – 78; Rule & John, 2011, p. 108). Dependability in this study was addressed by giving detailed descriptions of how the data were gathered and analysed (i.e. by applying an "audit trail", Bloomberg & Volpe, 2008, p. 78). Regarding the element of transferability of research, it should be noted that this does not necessarily mean that findings are generalizable to other contexts, as such. It rather refers to the potential of information gained in one context being useful (Bloomberg & Volpe, 2008, p. 78) or applicable to others in similar contexts. Transferability was created in this study by the use of thick descriptions (Rule & John, 2011, p. 108) and the provision of detailed contextual information, thereby aiming to provide a comprehensive realistic picture of Tatjana's world to the reader (Bloomberg & Volpe, 2008, p. 78).

I was guided by the latter criteria during my research and, in addition, incorporated Finlay's (2006) five dimensions of evaluating the outcomes of a qualitative research study to monitor my research process. Finlay refers to these five dimensions as the "5 C's" (p. 322): clarity, credibility, contribution, communicative resonance and caring.

I regularly asked myself the following questions:

*Clarity:* Does my research make sense? Is it systematic, coherent and described clearly (Finlay, 2006, p. 322)?

*Credibility:* Do my findings fit the evidence and are they convincing? Are my interpretations plausible and justified (Finlay, 2006, p. 322)?

*Contribution:* Does my research contribute to the discussion and knowledge of an issue or facet of human social life? Is it empowering or does it enhance growth? Does it challenge assumptions, sowing the seeds for possible change? Although this is a study of limited scope, does it provide guidance for future action? Does it create a thought-provoking foundation for future research (Finlay, 2006, p. 322)?

*Communicative resonance:* Do my words convey Tatjana's story accurately? Are my research findings adequately clear or powerful so as to engage readers? Do my findings ring true to the potential readers' own experience or understandings? Or do they perhaps challenge the readers' complacency about the topic under investigation (Finlay, 2006, p. 322)?

*Caring:* Did I respectfully and sensitively consider Tatjana's and other parties' safety and needs? Was I reflexive with regard to the manner in which meanings were elicited? Was ethical integrity demonstrated and did I, as the researcher, show concern about the impact of the research (Finlay, 2006, p. 322)?

### **3.7 CONCLUSION**

This chapter presented a comprehensive picture of this study's research design and methodology which was executed in order to answer the research question regarding Tatjana's experience of inclusion at a HEI as a student with CP. The following chapter presents the research findings.

## CHAPTER 4: FINDINGS OF THE STUDY

“I have something to say”

(Tatjana, 2012)

### 4.1 NARRATIVE ANALYSIS

#### 4.1.1 Introduction

This section offers a narrative analysis of the study, exploring Tatjana’s university experience as a student with CP. Her story follows a traditional pattern of storytelling. It is told chronologically (punctuated here and there by my reflections) incorporating an introduction (pre-university), a body (university) and a conclusion (post-university).

#### 4.1.2 Pre-university

Tatjana was 26 years old when she was interviewed for this study. Her story begins on 28 December 1985, when her mother (carrying Tatjana in utero), her father and her uncle were involved in a flying accident in Texas, USA. The four-seater aeroplane in which they were travelling had crashed due to engine failure, leaving Tatjana’s mother and the pilot injured. The doctors in the hospital did not at that stage pick up that her mother’s placenta had ruptured and that Tatjana was at risk. A little more than two weeks later, Tatjana was born 10 weeks early. Her mother had gone into labour prematurely due to an infected placenta.

This was the unfortunate-fortunate day of January 14<sup>th</sup> 1986.

The doctors performed an emergency caesarean section, bringing Tatjana into the world blue, weighing a mere 1 kg and measuring 27 cm in length.

Not even the length of a ruler! All things considered, it could have been worse.

During her first year, Tatjana’s mother thought that Tatjana was showing developmental delays, but she was told by medical practioners that she was simply a new mother and since Tatjana had been born prematurely, that she should give it time. At 9 months Tatjana

underwent an operation to correct a bad squint in both eyes, which in retrospect should have been a sign then of the possibility of CP.

We were lucky to have been in the USA to have had this operation early.

*Tatjana's reflections throughout the telling of her story were often accompanied by words of gratitude and good fortune which are indicative of her predominantly positive outlook on life.*

In February 1987, when Tatjana was just over a year old, she and her parents travelled back to their family farm in Namibia. It was only then during a doctor's check-up that she was diagnosed with spastic quadriplegia CP. At 15 months, Tatjana started her first therapy sessions: occupational therapy, speech therapy and physiotherapy twice a week.

Over the next few years her family grew, with the addition of two younger brothers. Her young parents had their hands full.

I think really a lot of credit goes to my parents for bringing us up the way they did, kind of balancing all sides and keeping the family together, and also explaining to my brothers that I was a little bit different, but yet, I'm not this alien in the family. I never felt like I was just somebody else. I was my parent's child as much as they were. My parents didn't do everything right, but they tried as best they could, and obviously I love them to bits.

When Tatjana was 7 years old her parents made the difficult decision to send her to a special school in South Africa, as they found that there were no suitable special schools for her in Namibia. This was an extremely difficult time for Tatjana, for although her foster family was very caring, Tatjana was very young to be so far away from home.

I did not want to be there. I missed my parents, I missed my brothers, I missed the animals, I missed the farm, I missed everything!

It was during her second year in South Africa that Tatjana was assessed and Tatjana's parents were told that Tatjana's I.Q. was below 90. This came as a jolting shock to her parents - they were not convinced that this was the case. She had a physical impairment, she had difficulty speaking clearly (at that stage), she had limited fine motor skills and



sensory integration problems, but as far as Tatjana's parents were concerned, Tatjana did not have an intellectual impairment.

My parents, thank goodness, always knew that I was very clever.

Tatjana's parents withdrew her from the special school and took her back to Namibia, where she was placed in a government school, being the first person with a discernible physical impairment to enrol there.

So, I was a pioneer at school, I was a pioneer at university. I've always been ahead of my time, which in a way is nice, but when it's busy happening to you, it is not nice at all.

Tatjana navigated her way through primary school, where she was first placed in a special class for some subjects and later "graduated" to "normal" classes for all her subjects. Initially, the teachers and parents of the other children in her class were apprehensive about having Tatjana in their class. The teachers felt that they were not adequately trained and that they would not be able to cope, and the parents felt that Tatjana would hold back the class and that this would impact negatively on their children.

So basically, I just had to prove them wrong, and I did.

*Tatjana's determination to succeed and to dispel any misconceptions about her abilities is a common theme throughout her story.*

While at primary school, Tatjana excelled in her language subjects (German and English) but experienced problems with mathematics and any work that involved visual-spatial concepts such as drawing. Tatjana admits that her brother, Aljoscha, frequently helped to relieve her mathematics homework load.

Teachers didn't really understand the way that I worked ... so there was always my brother doing my maths homework. He was two years younger than me, and he was just very good at school, generally, and also now in life, he is very academic. So, he always did my maths homework.

When it came to high school, Tatjana's parents placed her and her two brothers in another boarding school, which was further away from home. After a while it became clear to Tatjana that, as this school was geared for the sciences and Tatjana was struggling with mathematics and physical science, she would not be able to pass with a matric exemption, which she needed to be able to apply for university. She voiced her concern to her parents and a head teacher. Her parents were supportive.

I'm lucky, my dad has a Master's degree and [my parents] are educated people. Not to boast, but they kind of talked to us about our futures and where we wanted to go and what we wanted to do. There was this option of studying, and I was like, "Yes, I want to go to university - that was my thing".

The head teacher, on the other hand, was not as understanding.

She said, "... but Tatjana, what do you want at university?" I'm like, what does anybody want at university? I want to study and I want to become something, but she really didn't understand how it entered my mind [to want] to go [to university].

Tatjana resolved to prove the head teacher wrong. Her mother had seen an advertisement for a college in South Africa that seemed to meet all of Tatjana's subject requirements. After visiting the college and after much deliberation between her parents about what would be the best thing to do for Tatjana's future, they decided to send her to the college for grades 11 and 12. Tatjana was keen to go and within a short period of being there, she started to show her true colours.

That was the best thing that ever happened to me, because low and behold, at the end of grade 11, I was top of grade 11. I got the academic shield. Normally I don't worry about these things, but that was a very important prize for me. But [at this college], I could drop maths. I could drop maths and physics, and the day I did that, everything just fell into place. I could focus on what I was doing well, and I could just work hard, and it would pay, whereas in my other schools, I worked hard and it never paid, because maths and physical science were kind of always on my case.

Although grade 12 turned out to be a very hard year, Tatjana went on to pass matric with distinction. She was elated, explaining that

People never thought I would ever make it this far, and now I had shown them all, and who could now tell me... I was Miss Invincible, and everything was going to go right now.

Tatjana had been accepted to study a Bachelor of Education (BEd) at SU the following year and had high expectations that her academic journey would be far easier from that point on. Tatjana did not know then what lay ahead at university.

### 4.1.3 University

Tatjana's grandparents brought her to Stellenbosch, as her parents were abroad at the time.

I came there and it was bad ... I was just this lost person.

Nobody had cautioned her that there would be road-works ahead. When she and her parents had visited the campus prior to applying, they had been shown various places that accommodated the physically disabled, but, it turned out that these were not the places that Tatjana would be frequenting as an Education student.

She was allocated a room in a non-accessible university residence where she found (amongst other things) that she could not use the showers as the taps were out of reach. In addition, she did not have someone to show her where essential things were, such as where the relevant buildings were and how to navigate her way to them. She described her first few weeks of student orientation as extremely taxing.

It felt like they were focussing on so many unimportant things instead of focussing on the important things. We had *Jool*<sup>12</sup> and all of that, and people always go on how great *Jool* is, and *Jool* here and *Jool* there, but in my case *Jool* was the worst thing that could have ever happened to me. You have to

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<sup>12</sup> Jool is the Afrikaans term for Rag

waste all your time with pointless activities, whereas you actually need your time to find your way around, to see what works, to see where you are and where you need to be, and to figure out all these things before you actually go to class ... I actually needed someone to take me by the hand quite literally and say, "This is where the lift in the Neelsie [student cafeteria] is, this is your faculty, this is where the bathroom is that you can go to", because it's all there, but I had to find the stuff!

### *No thoroughfare...*

Upon arriving at the Education Faculty, Tatjana discovered that she could not use the front entrance and that the existing ramp for wheelchair users at the side entrance was too narrow for her mobility scooter and, therefore, the ramp had to be widened.

That took three months, and for three months of your life you don't know whether you are coming or going, and you don't need that. You are really stressed out and lost as a first-year student and academic, and how are you ever going to cope? You don't need people saying to you, "Oh yes, but now you have to wait for three months for you to properly enter your faculty!"

Tatjana encountered many barriers during her first year. Getting around was a problem. She had to learn how to drive a mobility scooter (until then she had used crutches only); she had to learn how to get from point A to point B (which was difficult due to her limited spatial orientation skills); and there were frequently cars blocking the pathways and entrances.

Then you have these thousands of cars standing in your way and you have people telling you, "But you can just go round this way, just take the other route," and I'm like, "Dude, you don't understand. There is no other route I can take. This is what I know!"

Keeping up with the busy first year time-table and curriculum had its difficulties, too. Tatjana found that there was not enough time for her to get from one class to the next punctually and there was not enough time to go to the toilet between classes either.

After a couple of months it became too much. Fortunately, someone took her to the university's Centre for Student Counselling and Development, where she was counselled by one of their psychologists. Tatjana told the psychologist that

I haven't been to the toilet today, I haven't eaten since breakfast today, and I haven't slept more than four to five hours a night for the last two months.

The psychologist (with whom Tatjana found she could identify, as he was blind) immediately saw that things as they were had to change or else she would run the risk of becoming seriously depressed. The psychologist and Tatjana summarily set up a meeting with the lecturer concerned to discuss viable options to support Tatjana and her studies. They took along another psychologist. During the meeting Tatjana discovered that she not only had to negotiate physical and logistical barriers on campus, but attitudinal barriers too.

Now I'm laughing about it, and it really is funny, but then it wasn't so funny, but now it is. [the lecturer] never talked to us, neither to me nor the blind psychologist. He/she talked about us, but he/she only talked to the one "normal person", in inverted commas, in the room (the other psychologist).

The lecturer did not think that teaching was a suitable career choice for Tatjana.

(Professor Dr So and So) basically told me in so many words – he/she didn't tell it to me directly, but you know, behind the scenes, in between the lines – "please leave".

Tatjana began doubting her decision to come to university. She was struggling - it certainly was not easy - but then it dawned on her that what she was experiencing was not only about herself and *her* academic journey, it was much bigger than that.

I just thought, "How many people has he/she actually sent home? How many people have actually believed him/her and said okay fine, university is not for me, and studying is not for me, and I will go home"? If this continues, then nobody ... things won't ever change.

Tatjana, determined as ever, decided to continue studying and it was agreed that she would take fewer subjects<sup>13</sup> per year to accommodate her mobility limitations. This meant that she would take longer than four years to complete her degree.

From 2007 to the end of 2009 Tatjana struggled on. She would encounter barriers, grapple with them and then negotiate a better route or path. She described these barriers as “the little things” that impacted heavily on her everyday functioning.

Getting into the building is one thing, but then come the lecture halls... so it's issues, issues, issues ...

*150 000 stairs ...*

The main lecture hall in the Education Faculty could be approached from the top with many stairs leading down to the bottom, where the lecturer stood. This was not an option for Tatjana as she wanted to engage with the lecturer – being so far back served no purpose. The other option was for her to enter from the bottom of the hall, which entailed Tatjana navigating five difficult steps to reach this entrance so that she could sit at the front.

This one person in the Faculty actually said to me, “Well, either sit at the back or don't come”.

This did not stop Tatjana. She crawled up those five difficult steps many times to reach her goal. After all, she was at university to learn!

*Blackboard writing ...*

My first year at university was basically dominated by the blackboard, and my fear of the blackboard, because we had this subject, “Board Writing” and we were supposed to learn how to write properly on the blackboard. Now, into the first few sessions, I figured out that there was no way that I could write

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<sup>13</sup> The terms ‘subject’ and ‘module’ are used synonymously in this study.

properly on a blackboard, because writing and standing on their own are two skills that are not so easy for me, and if you combine them, it's just chaos!

Tatjana had spoken to the lecturer about an alternative approach from the start, but the lecturer had said that they should wait and see.

So when the time came for that exam, I was just incredibly lucky. It was a practical exam. I was divided into a venue where ... the blackboards come right to the floor. So I went on my knees and I did my thing, and the lecturer came in and she was like, "What are you doing, you can't do this. You're not supposed to be on your knees, and what will the children think?"

This episode led to the lecturer creating an alternative assessment opportunity for Tatjana, where she wrote her exam on an overhead transparency and passed the subject.

In the (first few) years, people got so stuck on these little things. You know, if you can't do things like sports science, a sports lesson and a sport practical, if you can't write on the blackboard, if you can't play an instrument, then you can't be a teacher.

Not only did Tatjana encounter difficulties with infrastructure, curriculum and lecturers' attitudes, she also encountered attitudinal barriers from her peers. Students openly told her on various occasions that she was getting preferential treatment because of her impairment. For example, derogatory comments were made when she was moved to a more accessible, disability-friendly residence (which meant that a non-disabled student had to be relocated).

It was only in 2010 that Tatjana felt she had finally found "a freeway" and that she could cruise on auto-pilot for a while – her destination was in sight and she was very happy about that.

Me and the [lecturer], the new one ... sat down at the beginning of the year and we actually figured out how we would space out all the subjects that I had left to have me finish by 2012. So, in 2010 I had a plan, and I knew when I was going to graduate, whereas before the date of graduation was always unknown.

By 2012, the last leg of her journey, Tatjana had more or less run out of steam with regard to advocating.

The thing about the last two years I think is I've kind of not given up, but made peace with the fact that I am finishing this degree and I cannot change everything ... If they haven't listened so far, nothing else is going to make them listen now.

### *Poetic relief*

Tatjana often turned to writing poetry as a means to cope. She found putting her feelings down on paper helped to work through difficult legs of her journey. One such time was when she found herself trapped in a building after 5 o'clock with no one around to assist her.

#### ***Trapped***

*Does a tiger feel like this?  
Pacing up and down  
Behind sturdy iron bars  
Trapped  
His eyes dull and defeated  
Empty, save for the knowledge that he is unfree  
Not in control  
Never in charge of his own freedom*

*Look into my eyes right now  
They are dull and defeated  
Empty, save for the knowledge that I am unfree  
Trapped*

*I have run out of options  
And hot, raw panic rises  
My disability goes into overdrive  
Punishing me with the tenseness and un-coordination  
That I usually manage to keep well in check*

*Angry, burning tears force their way to the surface  
And if I could I'd kick myself  
I should have known  
I should have been more organized  
I should have checked  
While my limbs go off on their own accord  
My senses are heightened*



*And I am acutely aware of how ordinary  
How unproblematic  
The situation is for others  
They have so many options  
This would never leave them trapped and panic stricken  
If at all, it would be a problem in passing  
Before another plan was made*

*When I finally conquer the situation  
And the door releases me into freedom  
I do not feel like a conqueror at all  
I want to curl into a defeated ball of human  
And never rise again!  
People see my face  
Flushed with the residue of panic  
And they want to know  
But how do you tell them  
That all of this was about a bundle of keys, a remote and a door?  
I do not know  
So I shut down my words  
I give up on speech  
And I put the letters on paper instead*

Tatjana's poem 'Graduate in Waiting' was the last poem that she wrote before graduating. It encapsulates her gratitude to South Africa and her experience at university vividly:

***Graduate in waiting***

*Dear South Africa  
You are not my country  
But you and I  
Have crossed paths  
Rather often  
You have seen to my medical needs  
From the time I was very young  
And you've had  
A big part in my education  
I started school here  
I finished school here  
And now you have made me  
A graduate in waiting  
Dear South Africa*

*I have hated you  
I have loved you  
I have survived here  
I have lived here  
I can claim a small piece  
Of Matieland  
Because I've been here  
Six years of my life have been here  
Lived in a love-hate triangle  
Spanning first Monica, then Huis De Villiers  
The Faculty of Education  
And the Neelsie  
Dear South Africa  
My world is very small  
I have not been a real Matie in that sense  
I have not done all there is to do  
I have not seen all there is to see  
As a Matie  
Dear South Africa  
I have never, with intention, skipped a lecture  
I have never failed a module  
I have never gone to Varsity Cups and student hangouts  
In town  
The party and carefreeness of student life  
Was never mine  
Dear South Africa  
Instead  
I played Tug-of-War in meetings  
I had coffee with Deans  
I went to conferences  
I climbed the hierarchical ladder of our institution  
Until someone would listen  
And learn  
Dear South Africa*

*You call yourself the Rainbow Nation  
At great expense  
I have claimed my bit of the rainbowness  
It wasn't easy  
And South Africa  
You still have a ways to go  
But South Africa  
I am proud of you  
We've made it, you see  
Dear South Africa  
I thank you!*

After a long, gruelling, but successful academic journey Tatjana graduated *cum laude*, in December 2012. As the vice rector came down from his podium to award Tatjana her degree, her peers all stood spontaneously to applaud. Tatjana sat seated in a wheelchair at the front of the hall separated from the group – a Matie but not quite a Matie.

#### **4.1.4 Future prospects**

At the time of the interviews, Tatjana's plans were to teach in Namibia over the following five years to work off her bursary. She indicated that she might study further after that, and expressed her keen desire to work with and teach children with special educational needs.

#### **Post Script**

*Since 2013, Tatjana has been teaching at a school in Namibia. At first, she taught pre-primary school children. In January 2016, Tatjana started teaching Grade 3 at the same school. It is a move up the career ladder for her and a dream come true. She has had a handful of very supportive people surrounding her. Together they try to steer their school into more inclusive waters. Tatjana says that in many ways, it is a maiden voyage. Trial and error are her constant companions and she has had her share of stormy weather, but on most days she cannot believe how incredibly lucky she is to be where she is, right now.*

This section has portrayed Tatjana's life story in which I endeavoured to illuminate her academic journey - the barriers that she encountered and the pathways to her successes - spanning her pre-university leg to frame her story, her six university years, and concluding

with her future prospects. Important themes, plots, characters, conflicts and resolutions in her journey were thus highlighted (Smith-Chandler, 2011, p. 109). The following section looks more closely at the thematic aspects of Tatjana's story.

## **4.2 PRESENTATION OF THE THEMATIC FINDINGS**

During the data analysis process, four global themes stood out, namely: Tatjana's internal barriers, her external barriers, the role of support creating pathways to success, and Tatjana's reflections on what worked for her and her advice to future students with physical impairments. These global themes correlate with the original research sub-questions of this study (see 1.4).

### **4.2.1 Internal barriers**

As a student with spastic quadriplegia, Tatjana's inherent barriers (her physical impairments) impacted directly on her experience at university. The following three organisational themes were identified:

#### **4.2.1.1 Limited mobility and poor navigation skills**

Tatjana's mobility was limited to covering short distances with the aid of crutches and longer distances on a mobility scooter. In addition, her poor spatial orientation skills meant that traversing the campus on her own was difficult – becoming easily disoriented if she deviated from a known path.

... in that respect, I am like a blind person, only with eyes wide open ...

Due to Tatjana's limited mobility and poor navigation skills, her campus experience and access to all possible resources was restricted.

I think one big thing that comes to the fore is how small my world actually is. I would like it to be bigger, [but] by force my world is very small. I mean, in Stellenbosch I've lived between my res, which was first Huis Monica and then Huis de Villiers, the Faculty of Education and then the Neelsie. That is all that I've done, that is all that I know ...



should she find herself in trouble while out with friends, made her cautious to venture out of her comfort zone. Safety issues are discussed further in point 4.2.2.4 of this chapter.

## **4.2.2 External barriers**

As previously mentioned in the narrative analysis section, Tatjana spoke about the “little things” that were so easy for non-disabled students and yet had such a big impact on her academic experience. These “little things” were frequently external elements. The following external barriers were identified as organisational themes in this section:

### **4.2.2.1 Outdated and disability unfriendly infrastructure**

The university’s infrastructure was not disability friendly in a number of ways. Inaccessible pathways, buildings, lecture halls, lifts, toilets and computer rooms were frequent obstacles that Tatjana had to overcome. The campus was not conducive to Tatjana’s mobility scooter and many of the building doors and stairs were not based on UD.

When [my] computer broke... I [didn't] have email access anymore, and most people will say, “Go to Humarga”, or “Go to the computers in the Faculty of Education”, but I can’t get into Humarga, and I can’t really get into the Faculty to the computers at the Faculty because the doors are stupid and they don’t open the way I need them to open!

### **4.2.2.2 Uninformed and exclusionary decisions**

It’s almost like either they don’t do anything at all, or they just do things on their own accord, and then it’s also not right. Like they want to help me, but in the process, they actually make it more difficult.

Bad decisions were made on Tatjana’s behalf without consulting directly with her. For example, a disability-accessible toilet was created by converting one of the men’s toilets on the third floor of a faculty building into a space for Tatjana. Tatjana alone had access to the toilet by swiping her student card. This not only led to a few disgruntled male staff members who were then obliged to use the men’s toilet on a different floor, but also made it difficult for Tatjana to gain access to the space. In order for her to swipe her card, she had to kneel down, lay her crutches on the floor, remove her ruck-sack from her back, find

her card, swipe it, put her card back into her ruck-sack and then stand up quickly with her crutches and ruck-sack to get into the toilet area in time.

Other exclusionary decisions were made unwittingly. For example, decisions were made to move lecture venues without considering whether the buildings or venues were accessible to all.

#### **4.2.2.3 Curriculum restrictions**

As mentioned previously, the assessments for subjects like Sport, Art, Music and Technology were initially inflexible. Another curricular limitation involved main subjects that took place elsewhere on campus (outside the Education Faculty building). Tatjana's timetable did not allow enough time for her to get from point A to point B in time.

These kinds of subjects that were happening outside of the Faculty of Education, they really kept me back. I mean, it became clear that I had to extend my programme, but had it not been for the subjects, the main subjects that were out of the Faculty, I would have maybe done it in five years.

#### **4.2.2.4 Being at the mercy of others**

In addition, Tatjana's inescapable necessity to be dependent on others to assist her and the consequent frustrations was an added stressor. Many of Tatjana's daily movements/activities involved relying on other people to attain her goal. For example,

The first term we had this thing where every Thursday we would have to go into a Grade R class for the morning. I was very scared about that because of transport and how would I get there, trying to figure out all the logistics, and also trying to get a school to accept me, because it's not fair on the school if you don't tell them who I am and what I need, but then you're also scared the school will say we can't handle this, we don't want this.

#### **4.2.2.5 Safety issues**

Apart from the logistical aspects of the time between lectures being too short and the distances between lectures outside the Faculty of Education being too long, the issue of



safety was paramount to Tatjana. If she deemed a situation to be unsafe, it became a barrier to her academic experience. For example, Tatjana explained that

Sports Science is far from where I usually am, and I don't go with the scooter because it's far and it's crossing big roads, and I don't feel safe with that. So I always had to kind of organise myself to get to Sports Science.

#### 4.2.2.6 Attitudinal barriers

Attitudinal barriers manifested themselves in various ways, from stereotypical, prejudicial or inflexible ideas such as *a teacher writes on a blackboard*, to unwarranted discrimination when a former lecturer challenged Tatjana's dream of studying teaching on the grounds of Tatjana's physical impairment. At the time, Tatjana thought:

This is discrimination just as much as it would be racial, if you would discriminate against me based on race. You don't know me. I have all the marks (grades), I have everything that everybody else has otherwise they wouldn't have let me in in the first place.

Ignorance played a significant role, as in, a lecturer's initial concern that it is a risk to have a disabled person in one's class, or a lecturer being unfamiliar with adapted assessments.

Many lecturers are scared of the scribe... they don't really know how it works, and they can't imagine that something like that can actually work.

Careless remarks and delayed support due to indifference exacerbated the problem:

People told me to make plans with the USBD (SU Risk Management and Campus Security) when I had transport problems. Then (USBD would) say, "No, they don't do it", or "They only do it after dark", and then you explain to them who you are, but then you still have to get higher up and higher up. You have to write emails to the right people, but until you get to the right people that are high up in the system that would maybe tell the people at the bottom, "Listen, you are supposed to pick this girl up and take her," a week or two has passed.



Tatjana also spoke about the frustrations of having hidden impairments:

Should you see me today, you might want to question whether I really am a spastic quadriplegic. The signs are definitely not as blatant today, as they were twenty years ago. A lot has happened since then. Besides all sorts of therapies, I underwent a drastic surgical procedure called a Selective Dorsal Rhizotomy ... In consequence, the signs are more subtle now, which makes life all the more frustrating for me, because I constantly feel the need to uphold my credibility (as a person with a physical impairment).

#### **4.2.2.7 Technological breakdowns**

I don't have very many options in terms of helping myself when something goes wrong.

Tatjana's unavoidable dependence on technology (such as her cellular phone, airtime, computer, mobility scooter etc.) led to major stress if or when they failed or were inaccessible.

When the scooter broke, it's like (I couldn't) do anything. Basically, (my) room (became my) prison. And it's like I had to organise all these things, but to organise all the things to get the scooter fixed, to speak to my parents ... I mean a phone without airtime, I can't just go to the Neelsie to buy airtime. So, there's this whole snowball effect where (a broken scooter) doesn't only affect your academics but it affects your whole life. It's, it's like you can't help yourself because you can't just go and buy airtime...

The latter organising themes tie in with the next global theme of support.

#### **4.2.3 Support creating pathways to success**

Certain aspects of Tatjana's experience at university were aided by pathways that were cleared for her or pathways that she managed to clear for herself. The following organizational themes stem from the global theme of support creating pathways to success:

#### **4.2.3.1 Family support creating pathways to success**

Tatjana's family played an influential support role that contributed to Tatjana's success at university. Her strong bond with her parents and her two brothers is evident throughout her narrative. She indicates that she has never felt that she is separate from her family because of her physical impairment and was encouraged from a young age to have aspirations like her siblings. At university, although the geographical distance between Tatjana and her family made it difficult for her parents to provide hands-on support, they were always a phone call away. Tatjana attributes her ability to cope well to her upbringing. Tatjana's parents always encouraged her to speak for herself and to be as independent as possible. In part, her parent's values and beliefs moulded Tatjana to be resilient.

I was never taught to sit back, relax and welcome the shackles of disability. Instead, I was always encouraged to figure out what I want and to go for it, head on, even though it mostly means head on collisions.

#### **4.2.3.2 University staff and students creating pathways to success**

Certain external influences and factors led to pathways to success for Tatjana as a student with CP in higher education. The proactive actions and decisions made by certain university staff members facilitated Tatjana's resilience and success.

Accommodating, supportive staff (lecturers, administrators, and psychologists at the SU Centre for Student Counselling and Development), and a few of Tatjana's peers and classmates, all influenced Tatjana's university journey for the better.

For example, a new lecturer in Tatjana's second year who was open to accommodating Tatjana's needs allowed her to continue her studies and a change in many of her lecturers' attitudes over the years enabled Tatjana to progress.

After March (each year) when the first tests are written and (the lecturers) actually see how everything works, and they actually see how well I do in the tests and how well I do in class and so on and so on, and that I'm actually not very different to other people in many ways, and that I'm actually an asset to the class in various ways, then they kind of calm down. By the end of the year I've had lots of lecturers come to me and say that they wish they'd have

known, and they're sorry for thinking whatever they did. Not necessarily that they acted badly or whatever, but I can just see that they are now, I've kind of turned them around and changed their way of thinking, which is good for whoever comes after me ...

These supportive people that Tatjana encountered along her academic journey at university were crucial path-makers. Through their actions or decisions, they created the opportunities for Tatjana to succeed.

#### **4.2.3.3 Disability friendly infrastructure and curricula creating pathways to success**

In point 4.2.2.1 it is mentioned that the physical campus was generally not easy to access, as far as Tatjana's mobility was concerned. However, once certain infrastructures were adapted, pathways became more navigable.

Basic support themes identified under this organisational theme are: ramps and stair rails; a disability friendly residence; and cement poles erected to prevent cars blocking thoroughfares (which also improved the safety of all other students). These elements designed for UD all enabled Tatjana to navigate more freely.

When Tatjana arrived on campus in 2006, access to paths, buildings and classrooms was limited. Once certain suitable infrastructure was put in place, Tatjana was able to move more freely. For example, the widening of the outside ramp at the Education Faculty at the beginning of Tatjana's first year, a railing being installed a few years later at the five 'difficult' steps in the Education Faculty where Tatjana had previously crawled up to get to the lecture hall, as well as the cement poles being constructed at the pedestrian crossing near the Education Faculty to prevent cars blocking the way during her last year, made things so much easier (See Appendix N for photographs illustrating the latter). How the railing came about is a good story:

So now I'm crawling up there [Tatjana laughs], here comes the – I think he's the [identifier omitted], or he was at that stage the [identifier omitted] [laughs]. It was very funny, awkward in a way. We never spoke, we never said anything. He looked at me, I looked at him, and he looked away. He looked at me, I looked at him, and he looked away. So there was this awkward moment

where he kept on looking at me and he looked away, and he looked at me and he looked away, and neither of us said a word. Two weeks later, this railing thing was there.

In addition, once a more flexible curriculum, assessments and a suitable time-table had been negotiated things became so much lighter for Tatjana, too.

#### **4.2.3.5 Resilience factors creating pathways to success**

Referring back to Chapter 2, two broad approaches to viewing resilience were discussed, namely the ecological approach and the newer socioecological approach.

Tatjana's *intrinsic resilience* / self-determination led to her success and is evident in her determination to complete whatever she started and to do it well. A clear purpose with a solid sense of identity stood out in Tatjana's dialogues.

I am an academic person, I understand theory; I know how to argue and write. That's my thing.

I am a teacher.

I also have ambitions and I also want to be someone. I want to be the person I choose to be, and not the one people expect me to be.

She holds a realistic outlook on life with regard to her capabilities and is flexible when necessary. She learns from mistakes, reflects on events and grows in the process. The following basic themes were organised under the organizing theme of *intrinsic resilience*.

*The role of gratitude:* Tatjana frequently expressed her gratitude. She indicated that she is grateful to her parents – for everything they have encouraged her to do and for the way they raised her and her brothers. She shows gratitude when support systems have been put in place for her (even if they were not necessarily helpful to her). She reflects her gratitude to South Africa for having hosted her as an “outsider” from Namibia (her early school years, ending off with university and graduation). She also shows her gratitude for her ability to persevere.

*The role of destiny:* Tatjana is not a religious person but often commented on elements that indicate that she believes that if things are meant to be then they will be. She also mentioned a couple of times that she is an academic and that it is her purpose in life to be a teacher. She knows that she cannot turn back the clock to take back the air crash that led to her physical impairment – there is a sense that her journey of being a person with a physical impairment is one that was chosen for her in order to break down walls and clear pathways for other students with physical impairments who will follow a similar path to hers.

#### **4.2.4 Tatjana's reflections and advice to students with physical impairments**

During her narrative, Tatjana reflected on and stressed certain practices that she indicated were important for her and for future students with physical impairments to consider when navigating their degree.

##### **4.2.4.1 The importance of advocacy**

I was always encouraged to speak for myself ...

Advocacy and breaking boundaries to create pathways was a strong message throughout Tatjana's narrative. Tatjana spoke about being a pioneer in many instances. She was often the first person with a physical impairment to be tackling a specific aspect in her life's journey and she felt a deep-seated need to advocate for others who might find themselves in the same situation. She felt that if things continued the way they were then nobody and nothing would ever change and it was important to her for others to benefit from her efforts - for all her struggles not have been in vain and for others to succeed.

In addition, Tatjana was invested in educating people about her physical impairment and how best to support her (and others with physical impairments).

It took me quite a long while to get many of the university staff to see the bigger picture basically, and to also see me for what I could do right, and what I could do that other people can't do, or what I had that other people didn't have, as a result of my disability, to kind of see it as a good thing, and not always as a bad thing.

Tatjana emphasised the importance of others having insight into her world - for others to see things from her point of view – so as to be better understood. Towards the end of 2008, for example, as part of a BEd subject proposal motivation piece, she wrote more than was required in order to provide insights about herself to her lecturers:

I am not including these writings, to make myself look good or to evoke your pity. I am including them, because I feel that it necessary for you to become aware. It is time for me to talk, in fact talking is overdue, because if I never talk, you will never know. If you know however, it might lead you to a better understanding of why I am holding on to this education degree for dear life.

Justice and the importance of equality and fairness was also a strong recurring theme throughout Tatjana's narrative. Advocating for putting things right at university was one of Tatjana's passions.

I don't want to push people that hard, but there comes a time where there's just nothing left. You have to shock them to kind of wake them up and make them see that this is serious.

Tatjana's tenacious advocacy cleared a number of pathways for herself and for future students with physical impairments. Part of her advocacy led to a few external barriers being removed (such as an accessible ramp being built at her faculty building).

In addition, Tatjana felt strongly about the importance of more students with physical impairments coming to SU to keep up the momentum of what she had started, so that more students with physical impairments would feel welcome and be successful at tertiary level.

It's really a tricky situation because if people don't come, things won't ever change, and if things don't change, then people don't come.

#### 4.2.4.2 The importance of being recognised as unique

Tatjana spoke about each form of physical impairment having its own needs and type of support systems. In addition, within CP itself, there are different levels of CP and therefore different needs and types of support for individuals here too. Tatjana also indicated that personalities and the levels of one's will to succeed differ from one person with a physical impairment to the next.

The need, therefore, to have individualised support mechanisms in place and the need to be consulted and considered when plans about one are being made was one of Tatjana's main messages.

However, the importance of being one of the crowd, is also important – fitting in.

#### 4.2.4.3 The importance of normalcy and being included

Tatjana's strong need to be 'normal' - to fit in – came up a number of times during her story. Tatjana finds herself being caught between the disabled and the non-disabled worlds. Being capable in so many ways but not capable enough - juxtaposed between the two worlds. This is illustrated in an extract from her poem called "Partner":

*My two metal friends<sup>14</sup>*  
*Were the barriers between us*  
*They make me different from you*  
*People call you normal*  
*And what am I?*  
*I am called physically challenged*  
*However, not challenged enough*  
*Too eager*  
*Too ambitious*

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<sup>14</sup> i.e. Tatjana's crutches

*Too able*

*Too normal*

*Normal yet different*

The aspect of being a true “Matie<sup>15</sup>”, which ties in with this notion of fitting in, came up in Tatjana’s dialogues too. Being a “Matie” is what many students at SU aspire to be (including Tatjana). Tatjana never really felt that this was achieved in her case. Two of the verses in her poem “Graduate in Waiting” encapsulate this feeling well:

*Dear South Africa*

*My world is very small*

*I have not been a real Matie in that sense*

*I have not done all there is to do*

*I have not seen all there is to see*

*As a Matie*

*Dear South Africa*

*I have never, with intention, skipped a lecture*

*I have never failed a module*

*I have never gone to Varsity Cups and student hangouts*

*In town*

*The party and carefreeness of student life*

*Was never mine*

A strong sense of regret – at having missed out – emanates from these verses. This feeling of not being fully included due to her impairments is found in other parts of Tatjana’s dialogue. For example, Tatjana spoke about having FOMO (the fear of missing out), as she was often aware of other activities happening on campus but was not able to attend them (either because they were physically inaccessible, impractical or unsafe).

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<sup>15</sup> ‘Matie’ is the nickname for a student studying at Stellenbosch University



#### **4.2.4.4 The importance of being independent**

The importance of being independent and being able to function as far as possible without others' assistance was another basic theme identified throughout Tatjana's narrative.

... it's a very big thing to not be in charge of your own life.

Independence as far as possible is important – this is what being a student is about – spreading one's wings and experiencing the world independently as a young adult. Opportunities for all students to experience their independence need to be facilitated.

#### **4.2.4.5 The importance of structure and planning**

A clear structure to one's studies and daily living needs to be established from the start of one's studies. The need for a good support system forms part of this structure. Tatjana emphasised the need for students with physical impairments to build good relationships with their lecturers and classmates. She frequently mentioned the importance of building relationships with people on whom she could rely when push came to shove, as she found that

There is no immediate catch up, support net when you ... fall.

With regard to planning, Tatjana spent a great deal of time co-ordinating and planning test arrangements. She would contact the lecturers well in advance to check whether all was in place. She would arrange a separate venue and a suitable person to transcribe her test answers (as, although she can write, she tires quickly due to her physical impairment).

You have to write emails to the right people!

Tatjana's view is that building relevant relationships, planning well, being well prepared and anticipating hiccups is crucial for things to fall into place and for pathways to be unhindered.

### **4.3 CONCLUSION**

This section presented the findings of the study. In short, the findings that were reported in this chapter, organised according to the research questions, were:

1. Tatjana's experience of barriers to learning at university:

Tatjana experienced both internal and external barriers. Her internal barriers were her physical impairments which limited her mobility and affected her navigation skills; limited her physical strength and motor skills; affected her reaction to sensory stressors and impeded reaction time which in turn created safety concerns. The external barriers that Tatjana experienced were: outdated and disability unfriendly infrastructure; technological breakdowns; curriculum restrictions; uninformed and exclusionary decisions made by others; being at the mercy of others; attitudinal barriers; and safety issues.

2. Tatjana's experience of support and her personal successes at university<sup>16</sup>:

The support elements that were found to be important to Tatjana's success were a supportive family; certain perceptive, proactive, and flexible university staff members and students; the installation of disability friendly infrastructure and suitable curricula adjustments; and Tatjana's own inherent resilience factors.

3. Tatjana's and the literature's recommendations to improve inclusive practices, especially for students with similar physical impairments in HE:

Tatjana emphasized the importance of self-advocacy; the importance of being recognised as unique; the importance of normalcy and being included; the importance of structure and planning, and the importance of being independent. The literature's recommendations will be incorporated in the discussion that follows.

The discussion and recommendations that follow in Chapter 5 draw on Tatjana's answers to the research questions formulated at the beginning of this study regarding her experience of inclusion at university, and attempts to synthesize the knowledge that was gained through this study and to propose suitable proactive practices for the future.

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<sup>16</sup> I have collapsed the two research questions regarding support and successes into one, to indicate how the support Tatjana received or created enabled her to succeed.

## **CHAPTER 5: DISCUSSION AND RECOMMENDATIONS**

“Resilience must go beyond being a phrase limited to understanding how individuals cope with adversity. It must entail a challenge to the very structures that create disadvantage, discrimination, and oppression”

(Prilleltensky & Prilleltensky, 2005, p. 24)

### **5.1 INTRODUCTION**

This study has sought to explore the experiences of a student with cerebral palsy at a HEI. By listening to Tatjana’s story and restorying it, valuable understandings about her journey at university were gained. In this chapter, the implications of the study are discussed. The complexities of supporting students with physical impairments in HE are emphasised and some recommendations for future practices and research are provided.

### **5.2 IMPLICATIONS OF THIS STUDY**

The conclusions below follow from the research questions and findings, addressing four aspects, namely: the implications of this study for the co-researcher, Tatjana; the implications of this study for students with physical impairments; the implications of this study for higher education institutions; and the implications of this study for theory.

#### **5.2.1 Implications for Tatjana**

This DSE study afforded Tatjana the opportunity to tell her story - to contribute her insights regarding the inclusion and support of students with physical impairments within HE in order to broaden the body of knowledge, to add her critical voice, and to validate that her voice matters.

Whether the research process was indeed truly emancipatory for Tatjana is difficult to measure. However, Tatjana did report that she found the experience therapeutic, enjoyable to share, and rewarding to find someone was interested in her story. She saw it as part of her journey as an advocate for students with physical impairments and regarded the study as pivotal – it is her legacy to students with physical impairments, smoothing the path for

others. Traina (2016, p. 16) suggests that the participatory and emancipatory approach to research should be viewed as “a process, rather than an outcome”.

### 5.2.2 Implications for students with physical impairments

Tatjana’s story contains a number of important findings or insights that may be useful for future students with physical impairments at HEIs. These findings correlate with findings in the literature, as discussed in Chapters 1 and 2 of this study. The importance of self-advocacy and advocacy for others is one such insight confirmed by Tatjana’s story and supported by the literature on students with physical impairments in HE (e.g. Lyner-Cleophas, et al., 2015, p. 3). The implication is that students with physical impairments need to be actively involved in educating HEIs in order to challenge the status quo, to re-align and institutionalise disability support and thus inevitably to encourage transformation. A benefit of this attribute (advocacy) for students with physical impairments, according to Prilleltensky, Nelson and Peirson (2001, p. 13 cited in in Prilleltensky & Prilleltensky, 2005, p. 13), is that the act of advocacy and taking part in social actions seemingly improves the student’s sense of self-determination, which in turn contributes to the student’s resilience and ultimate success – to go from being recipients to becoming agents of their own supports (Mortier, et al., 2011, p. 218). In addition, Beauchamp-Pryor (2012) posits that, in order to promote full inclusion, it is crucial that students with physical impairments become involved in decisions concerning policy and practice. The right to self-representation forms a part of this (ODP, 1997; DSD, 2016, p. 103). Moreover, there is evidence in the literature that for full inclusion of students with physical impairments to be established, students with physical impairments need to be seen as authorities of learning (Luna, 2009), and they may need to be willing to take on such roles in order to encourage change.

Another important finding of this research is that Tatjana experienced both external *and* internal barriers. Her internal barriers, her impairments, played a big role in the type of activities in which she could engage and the extended timeline within which she could realistically complete her studies. Tatjana accepted that certain elements of her experience at university could not be changed – her limited mobility and navigational skills, for example, could not be fixed – and she had to adjust accordingly. A conclusion that can be drawn from this finding is that students with physical impairments who register at HEIs cannot expect that the alleviation of external barriers alone will guarantee a positive

experience and ultimately, the successful completion of their studies. In addition, HEIs which perceive disability from a social model stance should be encouraged to rethink their approach, as the social model of disability disallows a consideration of the impact of impairment when supports are being formulated. A more interactional approach to supports (the social relational approach, for example), which takes cognizance of the interplay between systems and contexts, affords a more balanced approach to support.

A further insight gained from this study is that certain aspects of resilience, such as self-determination, a clear belief in oneself (Ancil et al., 2008; Lyner-Cleophas et al., 2015), a positive outlook on life (Lyner-Cleophas et al., 2014), a strong academic identity and good conflict resolution skills (Ancil et al., 2008) are important precursors to the perseverance, completion and success of students with physical impairments in HE, as was the case for Tatjana.

It therefore appears that internal barriers cannot be ignored, and need to be supported by a well thought out institutional individual support plan (often designed in process) that adopts a social-relational approach to disability. In addition, it appears that certain intrinsic attributes, such as self-advocacy, self-determination, a sense of optimism, a strong academic identity, as well as good conflict resolution skills, and the orientation to be willing to be involved in policy and practice decision-making processes, are favourable attributes for students with physical impairments to have to succeed in HE. Having said this, it should not be expected of students with physical impairments to be supercrips or super heroes (Hiranandani, 2005, Lyner-Cleophas et al., 2014), as Tatjana indicates, not all students with physical impairments are cut out to be tenacious. Institutions need to play an important role in supporting their resilience by creating pathways to success for these students, as discussed in the following section.

### **5.2.3 Implications for Higher Education Institutions**

It is apparent from Tatjana's story, and from the findings that sprang from her story, that there is much work to be done regarding the support of students with physical impairments in HE. Although South African HEIs have come a long way since 1994, with the formulation of progressive disability-friendly legislation, new legislation has not necessarily lead to immediate positive change (Lewis et al., 2005), and gaps between theory and the practical

implementation of legislation are to be found (DHET, 2012b). Tatjana's story is supported by the literature, which indicates that students with impairments in HE remain marginalized due to ongoing barriers (Tugli, 2013). The recently published *White Paper on the Rights of Persons with Disabilities* (WPRPD) (DSD, 2016) stipulates a number of requirements that HEIs are obliged to implement. Many of these requirements overlap with the findings of my study. One of these is that, in order to address barriers that students with physical abilities experience, HEIs need to create pathways to success (micro-mobilities) for all students through establishing inclusive, socially cohesive teaching and learning environments (Sayed, 2016, para. 20). For this to happen, HEIs need to encourage social cohesion and inclusion systemically - disability inclusion needs to be fully embedded in the general functioning of the HEIs at all levels - in their governance structures, their policies, their discipline-specific curricula, and in their lecture halls (Bell, 2013; DSD, 2016, p. 106; Lyner-Cleophas et al., 2014), challenging the current exclusionary underlying power structures and beliefs. It is insufficient for institutions to merely provide access to students with physical impairments to mainstream institutions (Pijl, Frostad & Flem, 2008 in Bossaert, Colpin, Pijl & Petry, 2013, p. 76). Ensuring a sustainable social dimension of inclusion for all students (Bossaert et al., 2013, p. 76), which includes the important element of participatory parity<sup>17</sup>, is required. This implies that the presence of hierarchical power relationships at HEIs, which often exclude students with impairments from meaningful participation (Luna, 2009), need to be addressed too.

Continuing the argument for systemically entrenched all-inclusive policies, since disability is a universal experience of humanity (Zola, 1989, p. 401), an awareness needs to be instilled in HEI staff and students that disability support is not only for a few students: anyone at any time can become disabled (permanently or temporarily) and all people coming to a campus would benefit from infrastructure guided by UD and a well thought out UDL policy, promoting universal access (DSD, 2016, p. 57). To reiterate, this should be visible in the university's infrastructure and policy documents across the board (Chataika et

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<sup>17</sup> Nancy Fraser's (2009, p. 16) notion of social justice where all are put on equal footing to interact as peers and that promotes equity of access as well as outcomes.

al. 2012, p. 389) and would benefit both disabled and non-disabled students and staff (Holloway, 2001, p. 612).

Other research has shown that when staff and student peers' minds shift from scepticism to the acceptance that students with physical impairments have a rightful place in HEIs, there is a significant increase in both throughput and the success rates of students with physical impairments in HE, as was evident in Tatjana's story. HEIs need to understand that being all-inclusive involves a mind-shift in decision makers, lecturers, support-staff and students' way of seeing and handling disability. There is thus a need for advocacy *for* students with impairments in HEIs by non-disabled advocates, too (King, Aguinaga, O'Brien, Young & Zgonc, 2010).

Furthermore, HEIs need to be cognizant that not all persons with disabilities have the same needs, as their impairments and contexts differ from one another: they are not a homogenous group but rather rhizomes that follow different paths. Thus, the relational nature of the impact of systems and the constraints of individual impairments need to be considered, and disability support reframed accordingly. The WHO's ICF bio-psychosocial approach may be a useful tool for HEIs to utilise as a point of departure when formulating individual support plans for students with physical impairments in their institutions. Furthermore, a strong message coming through in Tatjana's story is that students with physical impairments need to be consulted about decisions that affect them. This is a common point found in the literature (e.g. Beauchamp-Pryor, 2012; Lyner-Cleophas, et al., 2014; DSD, 2016, p. 101; United Nations, CRPD, 2016, p. 3) and should form part of the process when designing pathway supports such as individual support plans and UDL policies.

With regard to the problem of unreliable disability statistics (DSD, 2016, p. 22), the Washington Group on Disability Statistics series of disability questions could be explored by SA HEIs collaboratively, to record comparable statistics.

#### **5.2.4 Implications for theory**

DSE is a way to gain the voice of participants, so that they begin to act as agents of change. Further participatory research and research carried out *by* students who are disabled is recommended.

With regard to a suitable disability approach, many HEIs have adopted a social model of disability, although Luna (2009, p.160) and Bell (2013, p. 21) indicate that many HEIs' discourses are still based on the medical model of disability. I suggest that HEIs address both these aspects of individual impairment and social impact. An evaluation of the social relational approach to supporting disability and enabling inclusive facilitators is, therefore, a suggestion for future support. By adopting this approach, impairment is acknowledged and accommodated, and appropriate support is provided without persons with the impairments having to prove themselves to be super heroes. Ecological aspects impacting on the individual students should be identified and addressed where possible. Through this type of support, institutions, lecturers, administrators and peers can support resilience factors by creating pathways to success for students with physical impairments.

Furthermore, viewing resilience from a socio-ecological stance, which promotes a dynamic, interactive way of being, is more constructive and transformative than seeing resilience as merely an inherent factor that either exists within an individual or not.

### **5.3 RECOMMENDATIONS FOR FURTHER RESEARCH**

Further research that covers a larger student population (possibly including students with hidden impairments and non-disabled students' perspectives on disability and support) is recommended. In addition, research into the reasons for the relatively high attrition of students with impairments may be helpful – for their voices to be heard, too. Research involving focus groups of lecturers and faculty administrators' experiences with regard to disability and support suggests another paradigm to be explored. In addition, the lack of representation of black students with physical impairments in HE is a concern and should be investigated in the light of the strong need for parity of participation and social justice for all in South African HEIs.

### **5.4 STRENGTHS OF THE STUDY**

The main strength of this study is the choice of narrative participatory case study methodology, which allowed the true voice of the co-researcher, Tatjana, to be heard. As discussed in Chapter 3 of this study, case study research is not merely about doing research on or with a particular person or a specific context (Baxter & Jack, 2008, p. 556).



Case studies play an important heuristic role, as they have the potential to foster new or deeper understandings of the phenomenon (Merriam, 2009, p. 44), adding rich insights to the existing body of knowledge. In addition, the value of incorporating narrative methodology is that narrative inquiry is not simply about the telling of a story - *education* is at the core of narrative inquiry (Clandinin & Connelly, 1998, p. 246 in Huber et al., 2013, p. 213).

## **5.5 LIMITATIONS OF THE STUDY**

One of the limitations of this study is its scope. However, for the purposes of a mini-thesis, which requires that the research problem be of limited nature and scope, and that the research adds in a limited way to the theoretical and practical applications in the chosen field of study, DSE, it satisfies the requirements.

It could be argued that case study research investigating one individual's experience as a student with a physical impairment in HE is limiting. A counter-argument is that this possible limitation is also a strength, as it is an in-depth case study which affords a rich contribution to DSE (see 3.2.4.1. of Chapter 3, and 5.4 for further substantiation of this chosen methodology).

## **5.6 CONCLUSION**

In conclusion, it appears that what is vital for emancipation, transformation and social justice to come to fruition for students with physical impairments in HE is for HEI stakeholders to undergo a deep process of reflexivity – to identify and acknowledge the underlying hidden structures or practices that may be hindering students with physical impairments' positive experiences and successes in HE, to consult with students with physical impairments, and to subsequently put fully inclusive processes and policies in place that are entrenched in institutional practices, taking into consideration the inter-relational and dynamic nature of the ever changing relevant systems within this heterogeneous group.

Enhancing the resilience of persons with physical impairment takes more than just individual or personal change and others' caring. A change within the (institutional)

community, political change, and justice, are all crucial to support the resilience and success of individuals with physical impairments (and in this case, students with physical impairments in HE) (Prilleltensky & Prilleltensky, 2005, p. 24).

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## APPENDIX A

### Policy regarding students with special learning needs/disabilities\*

Approved by Senate: 25 November 2011

“... in the South African context a social model perspective involves recognizing, understanding and addressing disability as a human rights and development issue, where the key principles such as the non-discrimination and equity entrenched in our Constitution are appropriately applied to the experiences of disabled people in this country” (Council on Higher Education, p. 3).\*\*

#### CONTENTS

	Page
1. Background and the current state of affairs	2
2. Legislation and the National Plan for Higher Education	2
3. The position of Stellenbosch University	2
4. Definition	3
5. The rights of students with special learning needs/disabilities	3
6. Admission and registration	4
7. Accommodation	4
8. Physical facilities	4
9. Support services	5
10. University societies and clubs	5
11. Grievance procedure	5

#### 1. Background and the current state of affairs

In 1994, Stellenbosch University appointed an ad hoc committee to investigate the accommodation of persons with disabilities on campus (Rossouw, 2005). This process, up to the establishing of the Advice Forum for Students with Disabilities in 1997, is explained in full by Rossouw (2005).

As of 1 January 2006, the services for students with special learning needs/disabilities have resided under the Centre for Student Counselling and Development (CSCD).

Up to now the official policy regarding students with special learning needs/disabilities (SU, 1997) has directed the advisory role of the Advice Forum and basic service delivery to such students. The definition of disability, in terms of the previous policy, was based on the obsolete medical model of diagnostic entities. (See Brand (2005) for an explanation of the different approaches to defining the

concept disability. The main limitation in the previous process of service delivery to students with special learning needs/disabilities at the University was therefore the result of its decentralised nature.

## **2. Legislation and the National Plan for Higher Education**

Chapter 2 of the South African Constitution (1996)<sup>1</sup>, the Bill of Rights, guarantees fundamental rights for all South African citizens. This includes an equity clause, as well as the right to freedom from discrimination, based on a number of social criteria. Discrimination based on disability is one of these criteria. Thus, the Bill of Rights explicitly states that an individual may neither directly nor indirectly be discriminated against on grounds of a disability.

The Higher Education Act (1997)<sup>2</sup> requires that more effective measures be put in place to address the needs of students with special learning needs/disabilities and that specific changes to the system be considered, such as to the curricula and teaching, in order to accommodate a more diverse student body. The Higher Education Act (1997)<sup>3</sup> is also based on values that promote tolerance and an appreciation of diversity.

The National Plan for Higher Education<sup>4</sup> of 2001 also clearly states that higher education establishments should better provide for the needs of students who experience barriers to learning and development, specifically those that are intrinsic to disability. Therefore, these institutions have to indicate the steps and strategies, and the relevant timeframe, in their respective institutional plans for the optimal accommodation of such students. Higher education establishments are also expected to ensure, where possible, that students with physical disabilities can easily access physical facilities.

## **3. The position of Stellenbosch University**

The University's vision as set out in A Strategic Framework for the Turn of the Century and Beyond (2000) describes a campus culture that welcomes diversity of people and ideas. Students with special learning needs/disabilities enrich any environment with their unique knowledge, skills and characteristics, adding value to such an environment. The principle of fairness/equity in A Strategic Framework for the Turn of the Century and Beyond (2000) means that the University is committed to welcoming a student body that is more representative of South African society as a whole. This implies that more disabled prospective students should be encouraged to study at tertiary level. The principle of tolerance in the vision can be understood as a willingness to accommodate, as far as is possible, disabled students' diverse (and often complex) academic needs. A Strategic Framework for the Turn of the Century and Beyond (2000) sets out unequivocally that the University will "continue to give attention to accessibility for people with disabilities" (p. 20), and is viewed as the basis for this policy regarding students with disabilities. The University's vision and strategic priorities are therefore taken into account in this way.

The University is committed to the promotion of equal opportunities for all. The University protects, within reason, the rights of individuals with special learning needs/disabilities, as well as their participation in activities related to higher education. In addition, the University wishes to foster a positive and non-prejudicial attitude among staff and students toward persons with disabilities, and will, as far as is financially viable, provide for the needs of persons with disabilities.

With this policy on students with special learning needs/disabilities, the University wishes to serve the broadest possible spectrum of the South African society, within the framework of its goals and with due consideration of the viability of providing such a service on all the different levels, by:

- 3.1 accepting students with special learning needs/disabilities, who meet the necessary academic requirements, into the student community as fully integrated members;

- 3.2 providing for the needs of such students where necessary, where doing so is practicable and without impinging on the rights of other students; and
- 3.3 maintaining a central office and employing a specific person or persons to coordinate and promote academic accessibility and support for students with special learning needs/disabilities

#### 4. **Definition**

For the purposes of this policy, the term disability is used to refer to a person with (a) verifiable physical, non-visible, and/or psychological limitation/s that negatively affect(s) his/her daily activities in a specific way.

The implementation of this definition is done in accordance with the social model of disability, in which the focus is placed on the environment as a potentially limiting factor in terms of participating and engaging in activities, rather than on the diagnostic entities regarding disability as such.

#### 5. **The rights of students with special learning needs/disabilities**

This policy aims to provide for the needs of students with special learning needs/disabilities, within the limits of what is viable, and taking financial constraints into consideration, by:

- 5.1 facilitating access to modules, programmes, academic adjustments and/or aid;
- 5.2 keeping up to date about changes in the accommodation needs and other needs of the students with disabilities;
- 5.3 ensuring that all confidential information concerning the disability is only disclosed with the written consent of the student involved; and
- 5.4 promoting communication between staff members and students with special learning needs/disabilities, inter alia by obtaining academic and other information in an appropriate format

#### 6. **Admission and registration**

Admission to the University will not be refused on grounds of the prospective student having a disability, as long as the applicant meets the set academic requirements (which might in fact exclude persons with specific types of disabilities).

- 6.1 It is the applicant's responsibility to provide information concerning his/her disability in the application. In cases where applicants did not disclose their disability beforehand, the University is in no way obliged to provide support to any such student during his/her studies at the University.
- 6.2 Upon receiving the application/information, the Admissions Division will submit it to the Office for Students with Special Learning Needs (Disabilities) (OSSLN), which will identify the applicant's unique needs and the implications thereof by means of a questionnaire that the applicant will be required to complete.
- 6.3 After the evaluation by the OSSLN, faculties will be advised on the implications for support, including financial support, should the student be accepted. Faculties can then decide themselves what forms of support they can offer the student.

- 6.4 After admission, the student will be considered for the field of study of his/her choice. The Registrar's Division, the relevant academic department/s, other professionals and the OSSLN (in consultation with the applicant) will jointly consider recommendations for admission. If necessary, and with cogent motivation, certain measures will be taken to make teaching accessible for the disabled student concerned as well. Other adjustments (such as the use of special equipment by a lecturer and/or the student) may also be made, provided that such adjustments do not undermine the integrity of the graduate programme or make unrealistic demands on the lecturers. The student will be expected to provide a list of modules being followed, as well as his/her contact details to all the lecturers concerned, as well as to the OSSLN.

## 7. **Accommodation**

The existing accommodation/admission requirements and regulations, as they relate to placement in university housing, also apply to students with disabilities. Applications for admission to university housing will be considered and dealt with on an individual basis.

- 7.1 Special concessions will be made in the consideration of students with special learning needs/disabilities for admission to residence in university housing, as far as is practically and financially viable. Should a prospective student be dependent on the aid of an assistant, the accommodation of such a student together with the assistant will be considered, provided the housing units developed especially for this purpose are not already occupied.
- 7.2 Should a student with a special learning need/disability be accepted into residence or university house, the housing already equipped with such facilities will enjoy preference. The OSSLN may be asked to provide guidance to the management of the residence/house concerned in respect of the student.

## 8. **Physical facilities**

The University aims, where possible and financially viable, to improve accessibility to specific buildings and other facilities for students with special learning needs/disabilities.

- 8.1 In cases where a specific problem with access to an existing building is identified, either for a registered or prospective student, the University will attempt to rectify the problem as soon as possible. Such rectification may include a cost estimate or the consideration of other options (such as moving lectures to a more accessible venue). Academic and housing needs will enjoy preference.
- 8.2 Accessibility to students with disabilities will be taken into account as priority in the planning of new buildings and other physical facilities (for teaching, research, housing, sport, recreation, etc.) This also applies during the upgrading of existing facilities.
- 8.3 A representative of the OSSLN will maintain close contact with Facilities Management, in order to ensure that building project teams take the needs of persons with disabilities into account.

## 9. **Support services**

In consultation with the OSSLN attention will be given to the specific needs of persons with disabilities, while taking practical and financial viability into account.

The following divisions are involved in supporting these students:

- 9.1 The Division Student and Academic Support, and more specifically the OSSLN (point of service of the CSCD), coordinates all such activities aimed at supporting these students.
- 9.2 The CSCD facilitates, amongst others, personal therapy and development, extended time allowed for examinations and career development.
- 9.3 HUMARGA provides a variety of software packages, Braille facilities and other specialised tools.
- 9.4 The Department of Sport Science/Maties Sport provides for participation in sport, wherever possible.
- 9.5 If individual tutors are needed by students with special learning needs (even after their first academic year), the faculties concerned should, in conjunction with the OSSLN, perform a needs assessment for the following year and budget for tutor funding for those students. This informs the budgets for subsequent years. Should additional funds be required, the faculty may approach the OSSLN for support.
- 9.6 The student committee, Dis-Maties, is responsible for awareness drives, support and the promotion of the overall institutional climate with regard to students with special learning needs/disabilities. Dis-Maties receives organisational support from the OSSLN, but is a registered society like other student societies on campus.
- 9.7 Housing arrangements are finalised by the Centre for Student Communities with input from the OSSLN where necessary (see also point 7 in this regard).

## 10. **University societies and clubs**

When someone applies for membership of a University society and/or club, membership will not be refused solely because of his/her disability, but practical considerations and viability are significant.

## 11. **Grievance procedure**

In the case of academic grievances, the academic grievance procedure has to be followed via the Academic Affairs Council and the Dean's Office concerned if personal discussions between the student and the lecturer and/or departmental chair did not solve the problem.

Academic grievances are grievances regarding:

- the content and/or presentation of modules/graduate programmes;
- the learning environment and/or supportive aids; and
- the evaluation of graduate programmes.

Administrative grievances concern matters pertaining to, amongst others, registration, subject choice and study fees, and should be discussed with the administrative official involved, the faculty secretary, or, if necessary, the Registrar.

If the problem cannot be solved within the immediate environment, a written complaint should be filed with the Division Student and Academic Support, specifically the OSSLN. If a solution is still not found, the Director of the CSCD will then follow the official grievance procedure, in consultation with the Academic Affairs Council of the Students' Representative Council. As a last resort, the case should be reported to the ombudsman.

All other complaints (such as those of a physical or practical nature) can be reported to the relevant divisions or sections (such as Risk and Protection Services, Student and Academic Support, and more specifically the Centre for Student Affairs and the OSSLN).

First concept drafted on 18 May 2005, amended on 15 October 2011

Contributors to the drafting of this policy: HL Botha (Division Student and Academic Support), HJ Brand (CSCD), CD Cilliers (CSCD), H Keyser (formerly Student Affairs), and CC Rossouw (formerly of Department of Sport Science).

#### References

<sup>1</sup> South African Constitution, 1996. Chapter 2.

<sup>2</sup> Higher Education Act: Notice 1196 of 1997. S1.18 and S1.27.2.

<sup>3</sup> Higher Education Act: Act No. 101 of 1997.

<sup>4</sup> National Plan for Higher Education, 2001.

<sup>5</sup> Special Needs Education: Building an Inclusive Education and Training System, 2001.

#### Additional resources

Brand, HJ. 2005. A counselling model for students with disabilities. Paper delivered at the Conference on The Future of Social Services for Students. Catholic University of Louvain.

Rossouw, C. 2005. Gespreksvoeringdokument: Viserektor: Akademies insake die Adviesforum vir Studente met Gestremdhede. Stellenbosch: Stellenbosch University.

Stellenbosch University (SU). 1997. Beleid ten opsigte van Studente met Gestremdhede. Stellenbosch.

Stellenbosch University (SU). 2000. A Strategic Framework for the Turn of the Century and Beyond. Stellenbosch.

## **APPENDIX B**

### **Disability Unit 2016 brochure**

#### **Centre for Student Counselling and Development (CSCD)**

##### **OUR AIM**

Within a framework of equity and affordability, Stellenbosch University (SU) aims to serve the broadest possible spectrum of our diverse South African society by among other things:

- accepting students with special needs as fully-fledged and integrated members of the student body;
- creating a holistic awareness of these students; and
- designating the Disability Unit in the Centre for Student Counselling and Development (CSCD) to coordinate support services for SU students with disabilities.

##### **OUR VISION**

To create an enabling environment that holistically empowers students with special learning needs to achieve their full potential.

##### **OUR MISSION**

We aim to implement our vision:

- by creating awareness of diverse learning needs and disabilities among all staff and students on campus;
- by providing appropriate assistive technology, and expanding its use amongst students;
- by facilitating physical access to all environments on campus;
- by changing mindsets through proactive advocacy;
- through ongoing research and development of our services;
- by offering organisational support to Dis-Maties (a support body for students with disabilities run by students with disabilities);
- by enabling the effective integration of students with special learning needs through holistic support (with regards to academic, social and psychological issues as well as adaptations of the environment);
- by facilitating adapted assessments and curricula to enable optimal learning; and
- by rendering consultative support to staff in order for them to provide effective learning environments for students with special learning needs.

The DU is the starting point for coordinated support for students with disabilities. We provide support services specific to your needs. It is therefore important that you let us know about your individual circumstances and your needs. All requests for assistance must be accompanied by supporting documentation. Feel free to make an appointment and come in for a chat.

##### **1. What is a special learning need?**

People with disabilities include those who have long-term physical, psychological, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (UN Convention on the Rights of Persons with Disabilities, 2006).



## 2. How to apply for a degree programme and accommodation at SU

Apply on an SU application form or electronically (<http://www.maties.com/apply.html>). All students must write the National Benchmark Tests (NBTs). For any queries in this regard, contact the NBTs project team directly on [www.nbt.ac.za](http://www.nbt.ac.za). Extra writing time for the NBTs can also be arranged with the team.

## 3. Accommodation on campus

At present, there are five undergraduate women's residences (Heemstede, Sonop, Monica, Lydia and Irene) and two undergraduate men's residences (Simonsberg and Eendrag) with limited facilities for students with disabilities. Three mixed residences, Huis de Villiers, Concordia and New Generation, are equipped for senior students with disabilities. Metanoia, a mixed undergraduate residence, also offers limited facilities for undergraduates with physical disabilities.

In addition, as far as the budget permits, adaptations are made proactively and on an ad hoc basis in order to provide students with disabilities with the best possible access to the University's facilities. It is very important that you communicate your learning needs well in advance to the head of the residence in which you will stay or the DU, so that adaptations, if necessary, can be made. Please contact the University's Customer Service Centre at 021 808 9111 or [info@sun.ac.za](mailto:info@sun.ac.za) for any further enquiries.

## 4. Accessibility of academic buildings and grounds

The DU and Facilities Management are continually liaising with each other to improve the accessibility of academic buildings and grounds. Several academic buildings and other facilities are already fully accessible. New adaptations continue to be made as needs arise. Accessibility is a major consideration when new buildings and renovations are planned. Students are also encouraged to immediately report any accessibility problems to Facilities Management at 021 808 4666.

## 5. Sporting activities

The University offers a variety of sports for persons with disabilities. Contact Mr Wentzel Barnard on 021 808 3537 or [wwb2@sun.ac.za](mailto:wwb2@sun.ac.za) for more information

## 6. Special exams

Special arrangements, such as the allocation of extra writing time or the provision of documents in large fonts, may be made for tests and exams. Applications in this regard close annually on 1 May and 1 October. Apply via [www.mymaties.com](http://www.mymaties.com) at Tests/Examinations. Send your application to [skryftyd@sun.ac.za](mailto:skryftyd@sun.ac.za) or hand it in at the Examinations Office.

## 7. Converting study material into Braille

At HUMARGA (one of the University's computer user areas based in the Faculty of Arts and Social Sciences building) class notes, prescribed books, articles, transparencies, as well as test and exam papers are converted into accessible formats like Braille. This service is partly funded by the Lombardi Trust as well as the Carl & Emily Fuchs Foundation e-mail [braille@sun.ac.za](mailto:braille@sun.ac.za) for more information.

## 8. Special computers

Computers with screen-reading, magnifying and text-to-speech software (like JAWS for Windows and ZoomText) as well as a magnifier that enlarges text are available at HUMARGA (rooms 356 and 360) for the use of blind or partially sighted students. Braille printers are also available. These computers are connected to the University's network and provide access to e-mail and the internet. For enquiries about software or to purchase a laptop, please contact [braille@sun.ac.za](mailto:braille@sun.ac.za).

## 9. Library use



Students who need assistance and/or training to track down library and information sources may contact their faculty librarian (<http://library.sun.ac.za/English/aboutus/contactus/Pages/fbs.aspx>) via e-mail or visit them personally in the library. Both the JS Gericke Library and the Music Library (in the Conservatorium building) have a computer with JAWS for Windows and ZoomText which blind and partially sighted students may use to browse the library website (<http://library.sun.ac.za>).

## **10. Accessible parking**

SU makes special provision for the parking needs of students with disabilities. The DU can assist you to obtain a special parking disc which will allow you to park in the designated areas behind the booms. Contact Ms Melanie Willems [mwillems@sun.ac.za](mailto:mwillems@sun.ac.za) for assistance.

## **11. Academic workshops**

The CSCD offers several services to students with disabilities. Individual assistance as well as workshops pertaining to personal problems, career planning, stress management, job-seeking skills, time management skills, academic problems, study and thinking skills, amongst others, are provided. Sign Language classes are also offered. Visit [www.sun.ac.za/ssvo](http://www.sun.ac.za/ssvo).

## **12. Academic tutors**

Should you require academic support for individual subjects, please contact the relevant lecturers in your Faculty.

## **13. Mentors in residences**

All first-year students have access to mentors in the residences where they live and via the private student organisation (PSO) wards. These mentors can provide emotional and academic support. It is recommended that you keep in close contact with the chosen mentors in your residence or PSO.

## **14. Student societies**

You are welcome to join one of the many student societies on campus, such as Dis-Maties,

Maties Dance Society, etcetera. Visit [www.mymaties.com](http://www.mymaties.com) on the student portal for more information.

## **15. Financial aid**

If you need financial aid to help cover your study or accommodation fees, please contact Ms Lynette Williams at the Bursaries and Loans Division [lrw@sun.ac.za](mailto:lrw@sun.ac.za).

## **16. The Writing Laboratory**

The Language Centre's Writing Laboratory at 22 Crozier Street (opposite the Drama Department) offers help with writing skills and with the writing of essays and assignments. Contact Ms Anne-Mari Lackay on 021 808 2167 in this regard.

## **17. Campus Health Service**

Doctors and nurses are available at Campus Health Service at 7 Claassen Street (next to Metanoia residence) on the Stellenbosch campus. Phone them on 021 808 3496/3494. The Campus Health Service on Tygerberg campus is situated in the Student Centre in Francie van Zijl Drive. Their phone number is 021 938 9590. You may also contact the psychologist on Tygerberg campus at 021 938 9590.

## **18. Orientation session**

An orientation session for new students is offered by the DU during the University's Welcoming Week in January. Students are advised to attend this session and to remain in contact thereafter. It is also

recommended that students visit the University the year before they intend to study at SU and familiarise themselves with the University environment. Contact Ms Marcia Lyner-Cleophas on 021 808 4707 or [cleophas@sun.ac.za](mailto:cleophas@sun.ac.za) in this regard.

#### **19. SU Risk and Protection Services (formerly known as USBD)**

SU Risk and Protection Services take care of campus safety and also assist during emergencies on campus. Contact the control room on 021 808 4666 when you need their assistance. They are available 24/7.

#### **20. Crisis service**

A 24-hour crisis service for emotional and psychological emergencies is available on 082 557 0880. Also feel free to visit 49 Victoria Street during office hours (08:00 – 16:30) should you have a psychological emergency.

#### **VERY IMPORTANT!**

It is important that you are continually in contact with your lecturers regarding your needs and that you immediately discuss your needs with any new lecturers you may acquire during the course of your studies. Because you understand the challenges you face in your academic life better than the DU or anyone else ever will it is primarily your responsibility to ensure that your lecturers are informed of your needs. The DU will support you, especially at the start of your studies, but it is recommended that you build a good rapport with your lecturers so that they get to know you and remain aware of your needs throughout your studies. It is also vital that you inform us of your needs so that we can support you.

#### **CONTACT US**

**For any queries or comments, please contact or visit our Centre at 37 Victoria Street, Stellenbosch. You could enquire via**

**Braille Centre-specific queries:**

[braille@sun.ac.za](mailto:braille@sun.ac.za)

**Disability Unit- specific queries:** [disability@sun.ac.za](mailto:disability@sun.ac.za)

## APPENDIX C

### Institutional information letter



Dear

#### **PERMISSION TO CARRY OUT RESEARCH WITH A SU STUDENT FOR THESIS PURPOSES**

I am a MEd Educational Support student. The research project mentioned above will form part of my studies as a mini-thesis.

This study will be a disability study in education that will aim to gain insight into a particular student with a physical impairment's educational experiences of inclusion in higher education. The purpose of this study is to understand one student's perception and experience of learning at a higher education institution in order to facilitate the development of more inclusive practices for other students with physical impairments in higher education.

I will use qualitative methodology to investigate the thesis topic in the form of a case study. The participant in this study has been purposefully selected – being a student with a physical impairment (cerebral palsy) in higher education who is eager to be heard in order to facilitate change. The potential student participant is enrolled at SU at present.

I request permission from you for me to do this research at Stellenbosch University from August to November 2012. I will be careful not to let the research interfere with the student's studies. The interviews and contact sessions will take place after classes in an environment that will be chosen by the student.

I understand that this research cannot be approved by the Ethics Committee of the Research Sub-Committee A of the University of Stellenbosch until permission has been granted by you. I look forward to hearing from you.

Yours faithfully

Ms A Bucholz

**Supervisor:**

Prof Estelle Swart

**Dept. Educational Psychology Chairperson:**

Prof Ronelle Carolissen

## APPENDIX D

### Institutional permission to carry out research



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvenoot • your knowledge partner

13 August 2012

Mrs Alison Bucholz  
Dept Educational Psychology  
Faculty of Education  
Stellenbosch University

Dear Mrs Bucholz

**RE: The experiences of a student with cerebral palsy at a higher education institution: A case study**

Institutional permission is granted for the gathering of information from SU BEd General Education student, by means of a qualitative participatory case study, for the purpose of this research project. This permission is granted on the following conditions:

- the researcher has obtained the student's informed consent
- the student's participation is voluntary; he or she may withdraw at any time without negative consequence
- the data that is recorded must be suitably protected
- the researcher and co-researcher must act in accordance with SU's principles of research ethics and scientific integrity as stipulated in the *Framework Policy for the Assurance and Promotion of Ethically Accountable Research at Stellenbosch University*.

Best wishes,

Jan Botha  
Senior Director Institutional Research and Planning Division



Afdeling Institusionele Navorsing en Beplanning • Institutional Research and Planning Division  
Privaatsak/Private Bag X1 • Stellenbosch • 7602 • Suid-Afrika/South Africa  
Tel. +27 21 808 3967 • Faks/Fax +27 21 808 4533

## APPENDIX E

### Participant information letter

21 April 2012

Dear Tatjana

Thank you for being willing to take part in my research – it looks like it is finally going to come to fruition!

My topic has been approved by the Educational Psychology Department:

“The experiences of a student with cerebral palsy at a higher education institution: a case study”

I have made a good start on my first chapter and am waiting for my ethics application to be approved. I would like to do a series of interviews with you but can only officially begin with these once the ethics clearance comes through.

In the meantime, when it is convenient for you, I would like you to collate the following things:

1. Collect all relevant emails to and from lecturers, support services, etc. since you became a student i.e. emails that would illustrate problems, successes, etc.
2. Collect all journal extracts (I have some of your school practical extracts on file already); poems; documentation that would explain/illustrate your experiences and feelings – things that you are willing to share.
3. Continue to write in your journals, recording your experiences in 2012.
4. Draw up a timeline that illustrates your life thus far (from conception till now). It doesn't need to be in too much detail to begin with – we can sit together and discuss the important stages/events when it comes to interview time – add more detail then.

My aim is to gather as much authentic information from you in order to respect your “voice” in this study. I would like the thesis to be about *your* experiences at SU, reflecting your voice clearly - to see you as a 'co-researcher' (so to speak) to avoid your being the 'object' of study, as has been the trend in earlier studies on persons with physical impairments.

Remember, at no time do I want you to feel obliged to do these tasks if it is going to interfere with your studies – studies come first! Let me know at any stage if you are finding it too time-consuming or problematic. I look forward to our research journey together.

Yours sincerely

Alison

## APPENDIX F

### Participant's letter to the ethics committee

To whom it may concern

I, Tatjana [REDACTED], was approached by Mrs Alison Bucholz, Masters in Educational Support student. Mrs Bucholz told me about her research study and asked whether I would like to assist her as a co-researcher. She elaborated on her study, informed me on the exact proceedings and clarified my role as co-researcher. I voluntarily agreed to co-research with her.

I would like to be a co-researcher in this study, as I see in it the opportunity to be empowered and to empower others. I believe that by assisting as a partner, I can provide deep, valuable insights into the life of a cerebral palsied university student, and so further advance the field of disability studies. Although considerable efforts have been made and successes have shown, a lot still needs to happen before the physically disabled can live truly equitable lives in South Africa. We need every brick available to us to build a truly inclusive, equitable campus and society. I believe that our dually conducted research study can be such a brick.

As a partner in research and as a physically disabled person who seeks empowerment, as well as wishing to empower others, I would like to appeal to the Ethics Committee of the University of Stellenbosch to let me co-research under my full, real name. I do not feel comfortable adopting a pseudonym at all. Hiding identity, in my opinion, does not constitute empowerment. On the contrary, it signals the opposite, thereby defeating a big part of the purpose of this study. Also, as an important aspect of our research study, I would like to share with the public some of my unpublished poems. They provide a tangible, live insight without which the study would be painfully incomplete. I strongly feel that my poems should be included. I also feel that I want to publish them under my full, real name in the future. The idea of publishing a piece of work, under my name, when it has already seen the light of day under a different name (even if it is pseudonym) is highly unsettling to me.

For the reasons mentioned above, I would once again like to appeal to the Ethics Committee of the University of Stellenbosch to let me co-research under my full, real name. At this point, I want to reiterate that I voluntarily and knowingly agreed to co-research with Mrs Bucholz. The proceedings, as well as my role as a co-researcher, were communicated to me clearly and in great detail.

Yours sincerely,

Tatjana [REDACTED]

## APPENDIX G

### Participant's informed written consent form



STELLENBOSCH UNIVERSITY

### CONSENT TO PARTICIPATE IN RESEARCH

---

Thesis topic:

*The experiences of a student with cerebral palsy at a higher education institution: a case study*

Dear Tatjana

You are asked to participate in a research study conducted by me, Ms Alison Bucholz (BA Hons Counselling Psychology, HDE, FDE), currently a Masters student of the Department of Educational Psychology at Stellenbosch University. The results of this study will contribute to my thesis and, at a later stage, a research paper. You have been selected as a possible participant in this study because there is an apparent need to hear the stories of students with physical impairments' telling of their experiences in higher education in order to facilitate change.

#### PURPOSE OF THE STUDY

The purpose of this qualitative participatory, life history case study is to investigate and to understand your inclusive experiences as a student with cerebral palsy studying at Stellenbosch University. Societal, institutional and personal barriers and successes will be investigated in order to identify where better inclusive practices can be developed. This study will also hopefully serve as a form of support for other students in similar positions and hopefully be an emancipatory experience for you as co-researcher, too.

#### PROCEDURES

If you volunteer to participate in this study, I would ask you to do the following things:

Collate past written correspondence (emails, letters, notes) that you have had regarding your studies and experiences at Stellenbosch University.

Formulate a rough timeline of your life from pre-birth to now, illustrating highlights (or low points) in your life – this will serve as a point of departure during our initial interview sessions.

Be available for a series of interviews over a period of 2 months (approximately four 1 hour sessions) – times and venues to be determined by you.

Be willing to share some of your poems as data.

Be available as co-researcher, in the sense that you will have input in the research process and be able to proofread the thesis as it develops – to monitor the way the information is being interpreted and recorded.

#### **1. POTENTIAL RISKS AND DISCOMFORTS**

The telling of one's story has the potential to unsettle one - you may recall situations that may bring back uncomfortable memories. Should the need arise for therapeutic support then support will be made available from the SU student counselling services.

#### **2. POTENTIAL BENEFITS TO YOU AS PARTICIPANT AND TO SOCIETY**

The potential benefit to you as research participant/co-researcher is that the process will hopefully be emancipatory – your voice will be heard. Your story will be documented to bring about awareness and hopefully facilitate change for other students in similar positions.

This study hopes to be a positive contribution to the growing research in Disability Studies in Education, albeit a small contribution.

#### **3. PAYMENT FOR PARTICIPATION**

No payment for taking part in this study will be made.

#### **4. CONFIDENTIALITY**



Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. As you have indicated in your letter to the SU Research Ethics Committee that it is your wish for your real name to be used in the study, confidentiality regarding the use of your name will be handled at your discretion.

Confidentiality while the research is being carried out will be maintained by means of all data being kept in a secure place. Data recorded on my computer will be password protected and accessible only to me. Only you, my supervisor and I will have access to the transcripts and other written raw data. The digital records (audio-recordings recorded during our interviews) and transcripts will be kept safe for 5 years and will thereafter be destroyed. You will have the right to review and edit the audio-recordings during the research process should you wish to do so.

## **5. PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

## **6. IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact me, Alison Bucholz: [REDACTED]; email: [alisonb@sun.ac.za](mailto:alisonb@sun.ac.za); office no. 2018, Cillie Building, Ryneveld Street, Stellenbosch, or my supervisor, Prof Estelle Swart: [REDACTED]; email: [estelle@sun.ac.za](mailto:estelle@sun.ac.za).

## **7. RIGHTS OF RESEARCH PARTICIPANT**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject,

contact Mrs Malene Fouche (021 808 4222; [mfouche@sun.ac.za](mailto:mfouche@sun.ac.za)) at the Unit for Research Development.

<b>SIGNATURE OF RESEARCH PARTICIPANT OR LEGAL REPRESENTATIVE</b>
--

The information above was described to me by Ms Alison Bucholz in English and I am in command of this language. I, the participant and co-researcher, was given the opportunity to ask questions and these questions were answered to my satisfaction. It is understood that as co-researcher or partner in this critical disability study, I will be consulted regularly regarding the accuracy of the reporting. I will be able to monitor how my story is being told. I will also be involved and consulted in the design and implementation of the study.

I hereby consent voluntarily to participate in this study.

---

**Name of participant**

---

**Signature of participant, date**

---

**Signature of investigator**

I declare that I explained the information given in this document to Ms Tatjana [REDACTED]. She was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used (or necessary).

---

Signature of Investigator

## APPENDIX H

### Letter of approval for ethics clearance



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jou kennisennoot • your knowledge partner

#### Approved with Stipulations New Application

07-Aug-2012  
Bucholz, Alison AJ

Protocol #: HSS45/2012

Title: The experiences of a student with cerebral palsy at a higher education institution: A case study

Dear Mrs. Alison Bucholz,

The New Application received on 16-Jul-2012, was reviewed by Research Ethics Committee: Human Research (Humanities) via Committee Review procedures on 26-Jul-2012.

Please note the following information about your approved research protocol:

Protocol Approval Period: 26-Jul-2012 -25-Jul-2013

**Present Committee Members:**

Theron, Carl CC  
Somhlaba, Ncebarakhe NZ  
Viviers, Suzette S  
Van Zyl, Gerhard G  
Fouché, Magdalena MG  
Van Wyk, Berte B  
Hansen, Leonard LD  
Horn, Lynette LM  
De Villiers-Botha, Tanya T  
Newmark, Rona R  
Promsky, Heidi HE  
Beukes, Winston WA

The Stipulations of your ethics approval are as follows:

**Letter of Permission:**

Please forward a copy of the Stellenbosch University institutional permission letter to the REC secretary (Mr WA Beukes: [wabeukes@sun.ac.za](mailto:wabeukes@sun.ac.za)).  
The research cannot commence without institutional permission.

**DESC Application Form:**

The applicant's response to 6(f) should be 'Yes', as the research proposal (p. 7) and section 6.8.1 of the REC form indicate that, should the need arise for therapeutic support, arrangements will be made with the SU student counseling services.

**REC Application Form:**

Section 7.2: please indicate that the data will be destroyed after 5 years (as communicated on p. 8 of the research proposal).

**Research Proposal:**

The research methodology section (bulleted list on pp. 4-5) does not include detail on the nature and purpose of the information that will be gathered directly from organisations, etc. that is not available in the public domain (as indicated in section 2b of the DESC form). It also does not include detail on the nature and purpose of the anonymous information to be collected from available records (as indicated in section 5.1.5 of the REC form). Please provide this information in a short note to the REC.

**Standard provisions**

1. The researcher will remain within the procedures and protocols indicated in the proposal, particularly in terms of any undertakings made in terms of the confidentiality of the information gathered.
2. The research will again be submitted for ethical clearance if there is any substantial departure from the existing proposal.
3. The researcher will remain within the parameters of any applicable national legislation, institutional guidelines and scientific standards relevant to the specific field of research.
4. The researcher will consider and implement the foregoing suggestions to lower the ethical risk associated with the research.

## APPENDIX I

### Interview guide and time-line sample

#### Interview Guide

As an initial exercise, Tatjana will be asked to narrate a time-line indicating key periods of her life. This will be elaborated on during follow-up interviews.

Approximately 4 in-depth interviews will be carried out in which open-ended questions will be posed.

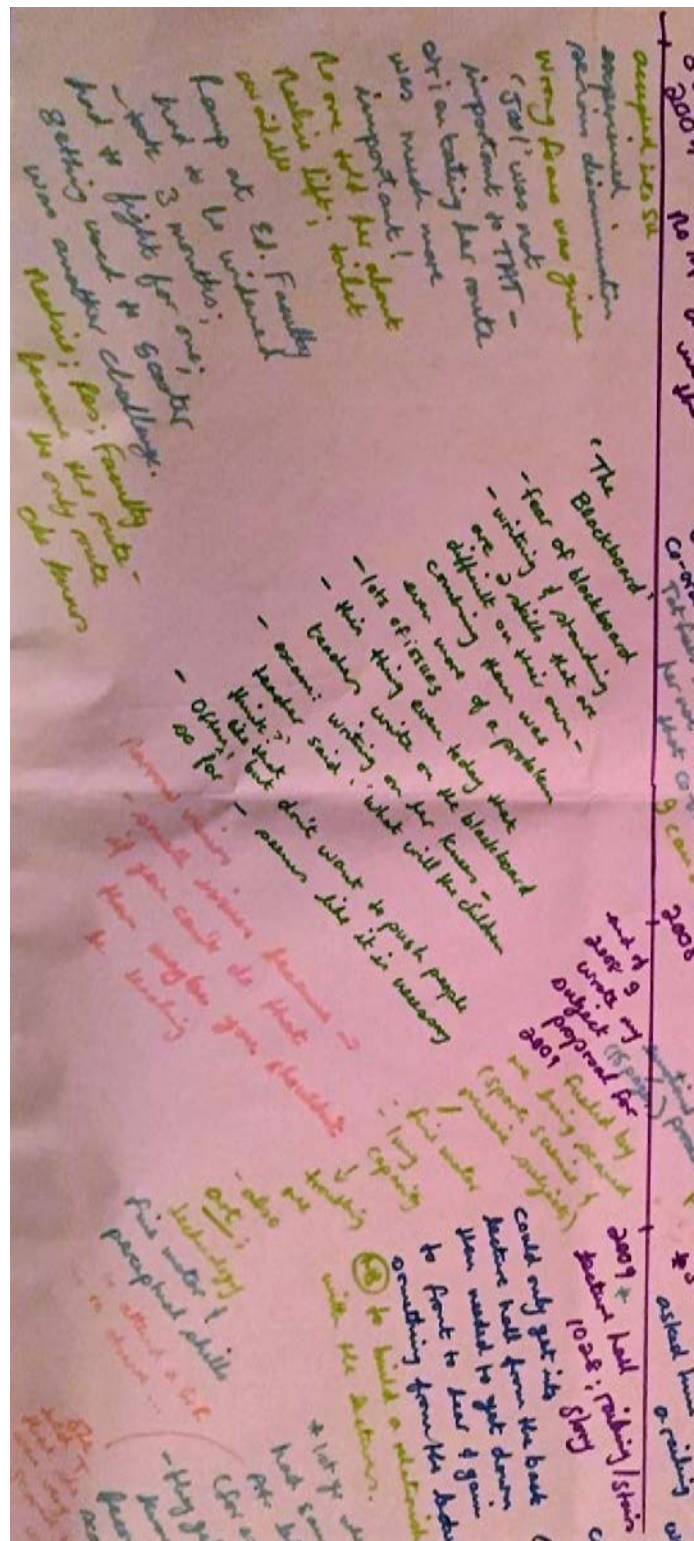
“Grand tour question”:

*What has your experience as a student with cerebral palsy been at SU?*

Tell me about your:

- Academic life?
  - 1<sup>st</sup> year? 2<sup>nd</sup> year? 3<sup>rd</sup> year? 4<sup>th</sup> year? 5<sup>th</sup> year? Final year? Reflections?
  - Lecturers?
  - Classes?
  - Classmates?
  - Assessments (tests, exams, other)?
  - Campus access?
  - Transport?
  - School practical teaching experience?
  - Nature of SU support?
- Social life?
  - Friends?
  - Relaxation activities?
  - Hostel experience?
- Family?
- Recommendations?

## Time-line sample



## APPENDIX J

### Extract from transcribed interviews

#### Interview 4 – 2012, 2011

##### Speaker Key

AB Alison Bucholz  
TA Tatjana

[Total time transcribed 29:06]

AB Okay, this is the closing off discussion of the last two years.

TA Yes, I haven't got that much to say, but the last time you said we should maybe talk a little bit more about 2012. The thing about the last two years I think is I've kind of not given up, but made peace with the fact that I am finishing this degree and I cannot change everything. I cannot make this a whole new institution, and I have had all the meetings with all the people, and if they haven't listened, I mean it doesn't help to have the same meeting with the same people 150 times over.

So, I've been there once, I've been there twice, I've been there three times, I am not going a fourth time. If they haven't listened so far, nothing else is going to make them listen now. I've become kind of less active, yes, but the one thing that really happened in 2012 that was really actually not my doing, it was Professor ..... doing, was we got to set up this pole, or these two poles.

You know which ones I'm talking about, because we always had this problem with the walkway, or not the walkway, but you couldn't get to cross the road to get to Education, because the crossing was open, but you couldn't get there because it was all closed off with cars. Opposite the Faculty of Education there's a big parking lot, so to the Faculty of Education, you cross the road, then you have a parking lot, and Admin A and all these things.

So we had a big problem with cars there, that they would always block that walkway, so to speak, and I always had to leave half an hour before my class started because of that specific place because most of the time there was a car and I had to make some crazy plan somehow. You don't even want to know all the things I did. But nowadays I actually bend the mirrors in. I don't care about the people's cars, the mirrors must just go.

The thing is, the scooter, my scooter is broader because I have the crutches on the sides too, so it's a mission. So anyway, there were always cars there, and no matter what we did and how many notices we stuck up, it didn't work. Then all of a sudden, early in 2012, I remember this morning I was still very upset because there was a car, and when I came back from my class the car had gone. Some people were working there with concrete, and the guy said to me it's for you so that you can drive past here. It wasn't my doing, and anyway, I was kind of enthused.

Interview 4 – 2012, 2011

## APPENDIX K

### An example of initial coding from the transcripts and Step 1 of Thematic Networks

Parents/Family

Safety

Problems/Issues/Struggling

Ltd to a small world

They don't understand

Lucky/Fortunate/Timing/Gratitude

Assets

Barriers

Pathways

Retrospection/Advice/Opinions/NB comments

Advocacy

<p>T So I think <b>the early years were pretty much <i>taken up with small little issues</i> that always ended up to if you can't do that, well then you can't study education. It took me quite a long while to get many of the university staff to see the bigger picture basically, and to also see me for what I could do right, and what I could do that other people can't do, or what I had that other people didn't have, as a result of my disability, to kind of see it as a good thing, and not always as a bad thing.</b></p> <p>2010, I think that was really the year where I felt that it had finally entered people's brains and then gotten to a stage where it wasn't any more "we will see what happens", or "we will see if this works". It was "it's going to work, now we just have to figure out how". <b>It took a long while for people to make that shift in their minds of not "let's see whether this will work, and we're not sure", actually expecting me to fail, to where it came to "okay, we're behind you now, this will work, what can we do". So, it took a while, I mean, the better part of three years [chuckles].</b></p> <p>I think <i>2010 was also my busiest year. I did eight subjects, um, but it was also my nicest, the year I enjoyed the most.</i> Um, a big part of that was that <b>all my subjects were finally in the Faculty of Education,</b> because that has always been a major issue to me, is</p>	<p>'little issues'</p> <p>Advocacy</p> <p>Attitudinal barriers</p> <p>Advocacy</p> <p>Attitudinal barriers</p> <p>Retrospection</p> <p>Asset/positive development</p>
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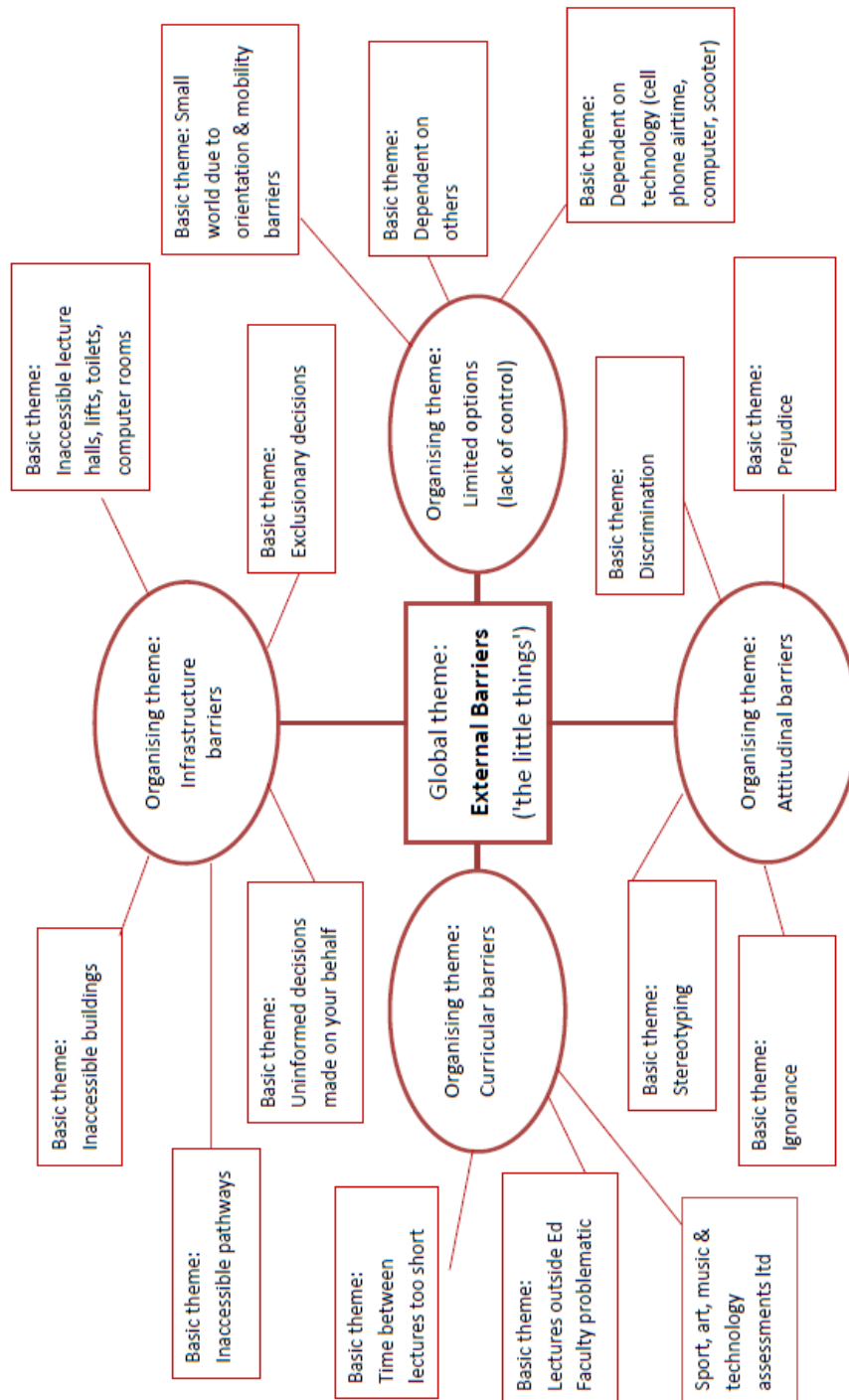
## APPENDIX L

Codes (Step 1)	Text chunks (Note: Varsity from line 768 in interview 1)
<b>Advocacy/informing/educating</b>	<p>"I have something to say" interview 1, line 621</p> <p>"I don't know, maybe it was just always my parents' policy, but as long as I can remember, starting then, I was always encouraged to speak for myself and my parents wouldn't speak for me. Later on my parents said to me this is what you're going to do, but you're going to do it on your own. You will make your own appointments. There were lots of incidents later where I had to speak to principals and so on, and I still do. I go to meetings with Deans, so I speak to people" interview 1, line 490 – 495</p> <p>"I also thought (that was also a very big thought), probably even bigger than the thought that <i>I will show you</i>, I just thought how many people has she actually sent home? How many people have actually believed her and said 'okay fine, university is not for me, and studying is not for me, and I will go home?' If this continues, then nobody... things won't ever change ..., but I knew what South Africa had been going through, this whole thing of we're trying to redress the past and discrimination.</p> <p>"I'm like ... this is discrimination just as much as it would be racial, if you would discriminate against me based on race. You don't know me. I have all the marks (grades), I have everything that everybody else has otherwise they wouldn't have let me in in the first place. Now this is discrimination, and if I just shut up, nothing will ever change and they will not learn. Obviously this vision wasn't complete, but I knew that I had to carry on, and I knew that I had to carry on not just for my sake, but for a bigger sake (cause)" interview 1, line 896 – 910</p> <p>"she (the lecturer) was quite shocked, and that happens quite often, that I don't want to push people that hard, but there comes a time where there's just nothing left. You have to shock them to kind of wake them up and make them see that this is serious. You know ...." interview 2, line 58 – 61</p> <p>"It took me quite a long while to get many of the university staff to see the bigger picture basically, and to also see me for what I could do right, and what I could do that other people can't do, or what I had that other people didn't have, as a result of my disability, to kind of see it as a good thing, and not always as a bad thing" interview 2, line 74 – 78</p> <p>"So I told her very politely, but very firmly in a way, that I've asked her for an alternative assessment, and she's never responded in a really conducive way ...</p>



## APPENDIX M

### Example of a Thematic Network of a global theme and organizing themes



## APPENDIX N



*Photograph 4.1*



*Photograph 4.2*



*Photograph 4.3*



*Photograph 4.4*



*Photograph 4.5*



*Photograph 4.6*

Photograph 4.1: Tatjana climbing the 5 difficult steps.

Photograph 4.2: Tatjana descending the 5 difficult steps.

Photograph 4.3: Tatjana at the 5 difficult steps after the railing was installed.

Photograph 4.4: Tatjana riding up the widened ramp outside the faculty building.

Photograph 4.5: A car blocking the pedestrian thoroughfare.

Photograph 4.6: The concrete pillar that was installed to stop cars from blocking the path.